

Open Research Online

The Open University's repository of research publications and other research outputs

Diabetes isn't an illness- It's a nuisance

Thesis

How to cite:

Smith, Julie Rosemary (2011). Diabetes isn't an illness- It's a nuisance. PhD thesis The Open University.

For guidance on citations see [FAQs](#).

© 2011 The Author



<https://creativecommons.org/licenses/by-nc-nd/4.0/>

Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.21954/ou.ro.0000ed88>

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's data [policy](#) on reuse of materials please consult the policies page.

oro.open.ac.uk

DIABETES ISN'T AN ILLNESS – IT'S A NUISANCE

by

JULIE ROSEMARY SMITH BSc PGCE

**A thesis submitted in partial fulfilment of the
requirements for the degree of
DOCTOR OF PHILOSOPHY**

**FACULTY OF HEALTH AND SOCIAL CARE
THE OPEN UNIVERSITY**

Date of Submission 31st August 2010

*Date of Submission: 27 August 2010
Date of Award: 23 May 2011*

CONTENTS

Abstract	viii
Acknowledgements	x
Glossary	xi
CHAPTER 1 DIABETES ISN'T AN ILLNESS, IT'S A NUISANCE	1–8
Introduction	1
CHAPTER 2 SETTING THE SCENE – LITERATURE REVIEW	9–54
2.1 Women and diabetes	11
2.1.1 Diabetes as a long term condition	13
2.1.2 Sexuality in women with diabetes	17
2.1.3 Eating disorders in women with diabetes	18
2.1.4 Multiple roles	20
2.2 Stress and diabetes	23
2.2.1 Stress as a concept	23
2.2.2 Stress stimuli	31
2.2.3 Stress and diabetes	35
2.3 Empowerment	44
2.3.1 Empowerment and diabetes	49

CHAPTER 3	METHODOLOGICAL THEORY AND PRAXIS	55–115
3.1	Theoretical framework – feminist theory	55
3.1.1	Feminist theory and critical social theory	56
3.1.2	Feminist theory and empowerment	59
3.1.3	Feminist methodology	62
3.2	Research paradigms	65
3.3	Ethics	75
3.4	Methods	78
3.4.1	Overview of research methods	79
3.4.2	Obtaining a sample	80
3.4.3	Stage One – Focus Group (n=5)	80
3.4.4	Stage Two – Survey (n=5)	89
3.4.5	Stage Three – Face to face interviews (n=23) and journal keeping (n=18)	92
3.5	Analysis	99
3.5.1	Interpretative Phenomenological Analysis (IPA)	99
3.5.2	IPA method	102
3.5.3	IPA analysis	103
3.5.4	Rigor of the research process	104
3.6	Writing up	107
3.7	The research participants	110
3.7.1	Ethnic background	111
3.7.2	Age	111
3.7.3	Work	111

3.7.4	Caring	114
3.7.5	Family structure	114
3.7.6	Duration of diabetes experience	115
3.7.7	Duration of insulin treated diabetes	115
3.7.8	Family members with diabetes	115
CHAPTER 4	DIABETES AS A NUISANCE	116-155
4.1	The women themselves	116
4.2	IPA thematic analysis	121
4.2.1	Constituent themes of the major theme of nuisance	121
4.3	Poetic representation of diabetes as a nuisance	149
CHAPTER 5	DIABETES IN DAILY LIFE	156–185
5.1	A typical day	157
5.2	Interaction between daily life and diabetes	161
5.2.1	Work and study related	163
5.2.2	Relationships	169
5.2.3	Social activities	178
5.2.4	Roles in daily life	180
CHAPTER 6	DIABETES AT TIMES OF CRISIS	186-236
6.1	Life events	187
6.1.1	Work and study related events	191
6.1.2	Redundancy of spouse	192
6.1.3	Bereavement/loss of a close family member	195

6.1.4	Divorce	198
6.1.5	Potentially dangerous situations	199
6.1.6	Concurrent events	200
6.1.7	No events identified	203
6.1.8	National and global events	203
6.2	Health related episodes	206
6.2.1	Psychological/emotional outcomes of living with diabetes	208
6.2.2	Physical episodes indirectly related to diabetes	222
6.2.3	Physical episodes related to diabetes	225
6.3	A complex situation	233
CHAPTER 7 EXPERIENCING STRESS AND MAINTAINING CONTROL		237-265
7.1	Experiencing stress	237
7.2	The relationship between stress and diabetes	241
7.2.1	One way relationship between stress and diabetes	241
7.2.2	Two way relationship between diabetes and stress	242
7.3	Defining the nature of stress	243
7.4	Diabetes-related stress	246
7.4.1	Other people as a source of stress	247
7.4.2	Short term complications	249
7.4.3	Long term complications	249
7.4.4	Self-management issues	250

7.5	Maintaining control	254
7.5.1	Being in charge	254
7.5.2	Physical control	258
7.5.3	Psychological control	261
7.5.4	Social control	263
Chapter 8	Pulling it into perspective - Discussion	266–295
8.1	Research findings	267
8.1.1	Experiencing stress and maintaining control	278
8.1.2	Diabetes as nuisance	272
8.1.3	Diabetes in daily life	274
8.1.4	Diabetes during times of crisis	279
8.1.5	A spiralling effect	281
8.2	The research process	285
8.2.1	Research methodology and methods	285
8.2.2	Reflexivity within the research process	287
8.2.3	Rigour within the research process	293
Chapter 9	Drawing to a close – Conclusion	296–299
Bibliography		300–326

Appendices

Appendix 1	Consent form for Focus Group	327
Appendix 2	Living with diabetes questionnaire	328
Appendix 3	Interviewing schedule	333
Appendix 4	Confidentiality agreement	338

Figures

3.1	Study design flowchart	79
3.2	Hierarchy of themes	110
4.1	Major theme of nuisance and its constituent subthemes	121
4.2	Constitution of subtheme of difficulty	122
4.3	Constitution of subtheme of obstacle	131
5.1	Daily life and diabetes	162
5.2	Subthemes of work and study related issues	163
5.3	Subthemes of relationship issues	170
5.4	Constituent subthemes of roles in daily life	180
6.1	Diabetes at times of crisis	187
6.2	Newspaper cutting included in Carol’s journal	205
6.3	Lynn’s depiction of the cyclical nature of the link between diabetes and her other long term conditions	213
6.4	Irene’s tip sheet on living with diabetes	220
7.1	Entry from Lynn’s journal	260
8.1	Diagrammatic representation of the spiralling relationship between stress and diabetes	282

Tables

3.1	Social profile of the 5 women in the focus group	84
3.2	Diabetes profile of the 5 women in the focus group	84
3.3	Questions for focus group discussion	88
3.4	Social profile of the 23 women interviewed	112
3.5	Diabetes profile of the 23 women interviewed	113
4.1	Clustered themes comprising the subthemes of practical difficulties	123
4.2	Clustered themes comprising the subthemes of physical difficulties	126
4.3	Clustered themes comprising the subtheme of emotional difficulties	128
4.4	Distribution of themes across women interviewed	147
6.1	Life events	189
6.2	Physical or psychological/emotional outcomes of living with diabetes	207
7.1	Responses to survey questions relating to the experience of stress and diabetes	239

ABSTRACT

Diabetes isn't an illness – it's a nuisance

Diabetes is a controllable, but not curable, long term condition usually self-managed in daily life. Much existing knowledge of diabetes is focussed on the biomedical and compliance models of care. In contrast, this thesis focuses on how women in midlife perceive the *experience* of living with diabetes.

An exploratory sequential mixed methods approach, within a feminist empowerment framework, examined the experiences of women aged 41-60 with insulin treated diabetes. Data collection methods included a focus group (Stage 1; n=5), survey (Stage 2; n=59), and face to face interviews and journal keeping (Stage 3; n=23 and 18 respectively). It is with the final stage that this thesis is primarily concerned. Ethical approval was obtained from an advisory ethics committee at the Open University.

The research questions were:

- What do women describe as stressful in relation to their insulin treated diabetes?
- What impact do these stressors have on women's lives?
- How do women with insulin treated diabetes interpret and manage their lives?

Two overarching and interlinked themes of *experiencing stress* and *maintaining control* were identified from Interpretative Phenomenological Analysis (IPA). Three other major themes were:

- *Diabetes as a nuisance*
- *Diabetes in daily life*
- *Diabetes during times of crisis*

Conclusions were that women in midlife who live with diabetes experience a range of stressors, and that there is a complex cyclical relationship between stress and diabetes with the potential for this to become a spiralling one. The originality of the study is in the area of identifying *diabetes as a nuisance*. Poetic representation of the data has been utilised to represent this theme, which will be used in dissemination of findings to both lay and professional audiences. There is the potential for both clinical application of these findings and future research.

ACKNOWLEDGMENTS

I would like to express my sincere appreciation to Dr Cathy Lloyd in particular and also to Dr Jeanne Katz, Professor Sheila Peace and Dr Lindsay O' Dell for their supervision and support in relation to this thesis. In addition, thanks to Dr Jessica Prior for her specialist input in relation to Interpretative Phenomenological Analysis. Thanks also go to Linda Camborne-Paynter for her help and patience with the preparation of this manuscript. There would be no thesis without the willingness and openness of the women who agreed to participate in the study, and they have my sincere appreciation for doing so. I would also like to acknowledge the friendship and encouragement of my colleagues, in particular Dr Tessa Muncey. Love and thanks go to my family, husband Steven and sons Josh and Sam, for providing me with technical support, and the confidence and encouragement to keep going.

GLOSSARY

Biomedical terms used within the thesis

Autoimmune disease Disease where an immune response occurs to the body's own tissues

Blood glucose monitoring Measurement of the concentration of glucose in the blood, often carried out at home.

Carbohydrate Food that can be converted into glucose as a source of energy.

Cardiovascular Circulatory system consisting of the heart and blood vessels

Cerebrovascular Blood vessels supplying the brain

Diabetes Disorder in which there is impaired utilization of glucose due to a lack of insulin

Diabetologist Doctor specializing in the care of people with diabetes

Dietitian Health care professional specializing in diet and nutrition

Dilatation and curettage Surgical procedure where tissue is removed from the lining of the womb

Gastroparesis Paralysis of the muscles of the stomach

Glucose metabolism Conversion of glucose into energy from carbohydrate

Glycosylated haemoglobin (HbA1c) Laboratory test to measure the average blood glucose level over a period of approximately 3 months.

Hyperglycaemia Raised levels of glucose in the bloodstream. This may lead to a life threatening coma, or contribute to the development of the long term vascular complications of diabetes.

Hypoglycaemia Lowered levels of glucose in the bloodstream, which may cause unpleasant symptoms such as feeling shaky and clammy, irritability, confusion and can lead to coma.

Insulin Hormone produced in the pancreas that regulates energy and glucose metabolism

Insulin Dependent (Type 1) diabetes Type of diabetes that requires insulin treatment

Insulin resistance Lack of physiological response to circulating insulin

Ketoacidosis Life threatening complication of diabetes due to raised blood glucose levels

Ketones Harmful acids produced when the body breaks down fat for energy production instead of glucose and occur in ketoacidosis

Non-insulin dependent (Type 2 diabetes) Type of diabetes treated with medication and/or diet.

Pancreas Organ of the body where insulin is produced

Pharmacology Study of the action of drugs

Podiatrist Also known as a chiropodist. Health care professional specializing in the diagnosis and treatment of disorders of the foot and lower leg.

Tracheostomy A surgical procedure in which an opening is created in the front of the windpipe (trachea)

Trapeziectomy Surgical procedure in which a small bone at the base of the thumb is removed, often in patients with arthritis

Vascular Term used in relation to blood vessels

Chapter 1

Diabetes isn't an illness, it's a nuisance

Introduction

The title of this thesis is a direct quotation from the words of a woman research participant who is living with diabetes mellitus.

Long term conditions are conditions which are not cured, but can be controlled, and include endocrine, neurological, respiratory, cardiovascular, cancers and mental health conditions. The majority of people (70–80%) with such conditions live within the community and are largely self-caring with a degree of support from health care professionals. A smaller percentage (15–20%) develops further health problems, and although remaining self-caring, requires greater input from health care professionals. Only 3.5% of all those with long term conditions require intensive professional care such as during periods of hospitalisation or acute illness. Their cases are more complex and they may suffer from more than one long term condition (DOH, 2005, p. 6).

Long term conditions are usually progressive in nature, and become part of the narrative of life for the person diagnosed with the condition. This involves incorporating the demands of the condition into the demands of everyday life, within a largely social, and sometimes medical, context. There may be periods of remission, when the condition plays a background role, requiring input which could be described as maintenance. These periods are in stark contrast to acute emergencies which may occur, and require immediate medical treatment and possible hospitalisation. Long term conditions may have

adverse medical, psychological and social outcomes for those with the condition and their families, in both the long and short term.

Diabetes is one such long term condition. Diabetes is essentially a disorder of glucose metabolism, with a relative (Type 2 diabetes) or absolute (Type 1 diabetes) lack of insulin produced within the pancreas, leading to high blood glucose levels (hyperglycaemia) within the bloodstream. Type 1 diabetes typically occurs in children and people under the age of forty. It is classed as an autoimmune disease, in which the body destroys its own cells, the beta cells in the Islets of Langerhans in the pancreas in the case of diabetes. This may be triggered by a variety of factors, including viruses, with the result that the number of insulin producing cells decline to the point that no insulin is produced. Insulin is essential for life as it has a major role in the metabolism of carbohydrate, protein and fat. In Type 1 diabetes, insulin is injected, either several times a day or administered continuously by means of a pump, in order to lower the blood glucose level. If too little or too much insulin is given, complications in the short or long term may occur. Too little insulin results in hyperglycaemia, which causes unpleasant symptoms and may lead to a life threatening condition called diabetes ketoacidosis in the short term. Events such as infections, trauma, surgery, or changes in medication may contribute to the development of this and require intense monitoring and adjustment of insulin dosages. In the long term, irreversible vascular changes to major organs of the body may occur resulting in impaired vision, renal failure, cardio and cerebrovascular disease, and disorders of the nervous system. Too much insulin may result in a low blood glucose level (hypoglycaemia), which can also lead to serious symptoms including coma, and in severe cases, death. Insulin administration may be painful for some people and can result in the development of lumps at the site of injection.

Type 2 diabetes occurs where there is a relative, rather than an absolute, lack of insulin. This usually occurs in older people, and is linked to obesity. The pancreas produces some insulin, but not enough for the body's needs, and a degree of insulin resistance may be present. Symptoms may not be apparent for some time, when there

may already be evidence of the development of long term complications. Type 2 diabetes may be treated by diet alone, tablet therapy (where the effect of circulating insulin is increased) and diet, or a combination of diet, tablet therapy and insulin. Diabetic ketoacidosis does not occur in Type 2 diabetes, but there is the risk of hypoglycaemia if tablet or insulin therapy is used. There is an increasing body of evidence which suggests that there is also the potential for psychological complications such as untreated depression to both impact upon, and be impacted by, diabetes, and to be implicated in the causation of the condition (Mezuk et al., 2008). However, Barnard et al's systematic review of the prevalence of co-morbid depression in Type 1 diabetes suggested that there were wide-ranging differences reported in the various studies (Barnard et al., 2006), indicating that the evidence in Type 1 diabetes is not as strong as in Type 2 diabetes.

Regardless of the type of diabetes, there is a need for blood glucose monitoring, often at home, but also at the hospital or clinic, to assess the effectiveness of therapy. This may be intrusive, and painful, for some people with diabetes. Diet is also a feature of diabetes management, however it is pharmacologically treated, and this may have social, as well as medical, implications. The support and management of diabetes within a health care setting is complex, and requires the input and expertise of a range of multi-disciplinary team members, including allied health care professionals such as dietitians, podiatrists, psychologists as well as nursing and medical professionals.

The exact number of people with diabetes is not known, as there are many people who have no symptoms of diabetes, but would fit the biochemical criteria for diagnosis in the United Kingdom. The overall prevalence rate is estimated to be just fewer than 3% of the population, with a total population of just fewer than 1.8 million. The forecast is for this figure to become 2 million by 2010, with another million undiagnosed. This has risen steadily since 1940 when the number of cases was estimated to be 200,000 (Diabetes UK, 2004, p. 10). The vast majority of people have Type 2 diabetes (approximately 1.5 million). Type 2 diabetes typically occurs with increasing age, with the majority being aged 45+ (617000 people). The largest numbers of people with Type 1 diabetes are in

the 15-44 age range (170000 people). There is a slightly higher prevalence in men than women when all ages are combined, with a steady increase in the prevalence of Type 2 diabetes with increasing age in both genders. Some ethnic groups have a higher prevalence of diabetes – 20% of the South Asian community and 17% of the African Caribbean community has Type 2 diabetes (Diabetes UK, 2004, p. 14). In Type 2 diabetes the prevalence is at least 5 times greater in South Asians living in the U.K. compared to white Europeans (Erens et al., 2001). There are also differences in the prevalence of diabetes according to socio-economic status. The most deprived in the UK are 2.5 times more likely to have diabetes and in the North East of England (an area with high levels of social deprivation), the prevalence of diabetes is 45% higher in women and 28% higher in men than the national average (APPG/Diabetes UK, 2006). Other groups with higher than average rates of diabetes include people with severe mental illness, people living in residential and nursing homes, prisoners, refugees and asylum seekers and homeless people (APPG/Diabetes UK, 2006). People in these groups are likely to have less social and community support with less access to health services, less opportunity for education and come from ethnic groups with a higher prevalence of diabetes.

This thesis focuses on the impact of living with diabetes, rather than the aetiology of the disease, that is: whether it is Type 1 or 2 diabetes, and the biomedical outcomes of diabetes. This focus has resulted from my practical experience with people with diabetes (often within their home environment), when it has been apparent that the issues they faced extended beyond these purely biomedical aspects. The lives of people with diabetes were made more complex by the fact that they had to take diabetes into account during their everyday lives. The aim for the person with diabetes is to self-care in order to maintain the balance between too much and too little glucose. For example, when exercise is undertaken, a decision must be made whether to increase the amount of carbohydrate eaten or to decrease the amount of insulin injected. Ironically, insulin therapy is one of the causes of one of the most distressing and feared short term complication of diabetes: that of hypoglycaemia. In my role as a specialist nurse in

diabetes, many clients described hypoglycaemia as being one of the most distressing aspects of diabetes, which had the potential to affect their daily lives in a negative way, with psychological and social effects. Women also had hormonal events such as pregnancy and menopause to contend with, which also had the potential to affect their diabetes control. Their lives were complex, with the majority of women combining paid work with childcare and other caring responsibilities, and this was particularly pertinent to women in midlife. They often made reference to being '*stressed*' and the fact that their blood glucose levels had a tendency to be affected at these times, which they could not attribute to other causes. The constraints of time within clinical practice did not allow for an in depth exploration of the experience of managing diabetes within the context of women's lives. The emphasis was largely on the outcomes of home blood glucose testing and/ or clinic measurement of glycosylated haemoglobin measurements (HbA1C), the latter giving an average reading of blood glucose during the three months prior to testing. Insulin adjustments were often recommended by health care professionals on the basis of these readings, with little attention given to the wider psychosocial context of living with diabetes. Medical interventions were decided upon using the dominant medical knowledge framework, with little attention to the women's experiential knowledge.

This experience in practice led me to determine the area of my research as being concerned with women's experiences of living with insulin treated diabetes, and whether the complexity of their lives was perceived as stressful. Women were chosen as the focus of the study as I was researching from the standpoint of a feminist approach, and one of the aims of the research was to give a voice to the women who took part in the research in terms of giving credibility to their experiential knowledge of living with diabetes, and to produce an account of this group of women's experiences. This will enable a more complete and shared understanding of the experience of diabetes to be created when this experiential knowledge is combined with the accepted biomedical body of knowledge of health care professionals. An empowerment approach is embedded within the research process, an aim that claims to be reflected within the NHS and Social Care model to

support people with long term conditions who are described as '*empowered and informed individuals working in partnership with prepared and proactive health and social care teams*' (DOH, 2005, p. 9). The rhetoric and reality of this statement will be considered, together with the implementation of an empowerment approach specific to diabetes care, which is recognised by some practitioners as a useful approach in the treatment of long term conditions. Empowerment as a concept in diabetes care is embraced within the National Service Framework for Diabetes (DOH, 2001), which sets the current standards for diabetes care.

Having determined the area of the research, a review of the literature suggested that there were few reports relating to the experiences of women aged between 41 and 60 living with diabetes. Much of the literature is concerned with the medicalisation of women's lives with diabetes such as hormonal events, eating disorders and mental health issues (Levine and Marcus, 1997; Linn and Bretzel, 1997; Lloyd et al., 1996). The overriding impression from this reading was that much previous research in these areas adopted a medical approach. This raised further questions about the position of women in a medical system in which the hegemonic discourse is that of patriarchy. Power in general has important consequences for women in a patriarchal world, where traditionally compliance with treatment has been used as a measure of success. This is at odds with the underlying philosophy of this study, in which compliance with treatment is believed to be an inappropriate term, with lay experience being valued equally alongside medical knowledge.

As a result of an initial focus group with women with diabetes, the following research questions were identified, which related to the complexity of living with diabetes and went beyond the biomedical model to incorporate psychosocial aspects.

Research questions:

- 1 What do women describe as stressful in relation to their insulin treated diabetes?
- 2 What impact do these stressors have on women's lives?
- 3 How do women with insulin treated diabetes interpret and manage their lives?

The following chapter reviews the literature in relation to what is known concerning women with diabetes, stress and diabetes, and issues of power and empowerment. This will lead to a discussion of how the topic was addressed in terms of the underlying research methodology and the development of appropriate methods of data collection. The research methodology is situated within a feminist theoretical framework, meaning research conducted by and for women in the context of this research. An exploratory sequential mixed methods approach was taken to data collection, consisting of a qualitative phase of a focus group, a quantitative phase of survey data utilising a Living with Diabetes Questionnaire (LWDQ), and a further qualitative phase consisting of semi structured interviews and journal data.

This thesis focuses on the data collected during the second qualitative phase of the research. The two preliminary phases identified that stress was an important issue for women in relation to diabetes. The subgroup of women in midlife (aged 41–60) formed the largest age group within the sample population, and fulfilled a wide variety of roles within the context of their lives. An interpretative phenomenological approach (IPA) was taken to data collection and analysis in the interview and journal keeping phase of the study, which focussed on the perceived experience of this group of 23 women.

One of the major themes that emerged from the data analysis is illustrated in the title of the thesis – *'Diabetes isn't an illness – it's a nuisance'*, and it is the concept of diabetes as a nuisance that is discussed in the initial data chapter. The second of the four data analysis chapters is concerned with diabetes in daily life and the third is concerned with diabetes at times of crisis. Both of these chapters illustrate stress in relation to

diabetes in the lives of this group of women. The final results chapter considers the overarching and interlinked themes of experiencing stress and maintaining control.

The data analysis chapters are followed by a discussion chapter, which places this research in the context of the existing literature and examines its contribution to knowledge. A key aspect of the originality of this thesis is taking the complexity of the combination of biomedical and psychosocial work forwards, as well as increasing the understanding of living with a long term condition. The final conclusions and recommendations are concerned with the application of the research findings to clinical practice in the context of government policy, and suggesting the way forward for future research.

CHAPTER 2

Setting the scene – Literature review

The introduction has argued that diabetes is a significant problem, with implications for public health and also for individuals with the condition. Diabetes is a problem in both medical and psychosocial terms; however the focus has traditionally been on medicalisation and treatment of symptoms. This thesis focuses on the psychosocial aspects of diabetes, and specifically on stress and the experience of stress, an area in which there has been very little research in diabetes (especially outside the laboratory). However, my clinical experience in relation to diabetes suggested that there was a greater complexity that was gender-related, and which went beyond the biomedical to a psychosocial approach. The focus in this study is on identifying what women find stressful in relation to their diabetes, and to study the impact that these stressors have on them, their roles, relationships and families. Women's experience of living with diabetes occurs within a rapidly changing social structure. This may include changes in the workplace, lifestyle, childcare responsibilities, advances in technology, changes in health care systems, breakdown of relationships or changes in family structure. How women perceive the experience of living with diabetes, and related stress, in such a social context will be the focus of this thesis.

The purpose of the literature review was to identify the existing literature in the areas of a) diabetes as experienced by women, b) the nature of the concept of stress and its relationship with diabetes, and c) the concept of empowerment in relation to diabetes. The review was then structured around the examination of each of these areas in turn with a view to identifying gaps in the literature and formulating research questions.

Having identified the research questions a further review with a focus on research methodology was conducted with particular reference to feminist research which also encompassed the concept of empowerment in research (see Sections 3.1–3.4).

The rationale for exploring the three areas identified within Chapter 2 was to identify literature specifically relating to women's gender-specific experience of living with diabetes, as opposed to diabetes in general. This area was the first to be examined as women were the focus of the study in both subject area and methodological terms. This was followed by an examination of the concept of stress and its relevance to diabetes, as this was a notion described by women I had encountered during clinical practice and wished to review existing evidence in this field in order to situate this research study within that body of evidence. The area of empowerment was reviewed in terms of both the existing evidence and also methodology. Empowerment was a principle that had the potential to underpin diabetes care, as opposed to the prevalent compliance approach, which my clinical experience suggested had the potential to have a disempowering effect. The traditional biomedical model of medical care in the United Kingdom is associated with compliance, where the patient adopts a largely passive role within the doctor–patient relationship. In a more complex scenario of care which moves beyond the biomedical, alternative models of care are necessary. Empowerment is identified as a standard within the National Service Framework for Diabetes (DOH, 2001, p. 91) and also within the NHS and Social Care Model (DOH, 2005) and underpins an emerging approach to diabetes care, where people with diabetes are encouraged to be active partners in their care.

Empowerment was also a concept with methodological relevance to a feminist approach to the research and the overall aims of the research of enabling women's voices to be heard within the hegemonic paternalistic discourse of medical knowledge. Empowerment as a concept has been threaded throughout the thesis where there is a more equal sharing of power.

From a thematic perspective literature searches for the period January 1970–December 2000 were initially conducted using CINAHL, MEDLINE, PSYCH INFO AND ASSIA. With the advent of the Web of Science, and the One Stop Search at the Open University, these tools were also utilised. An initial search for 'women' AND 'stress' AND 'diabetes' yielded no results. Separate searches were therefore performed for each of the three areas identified above, using specific terms included in the keyword or title – 'women' AND 'diabetes'; 'stress' AND 'diabetes'; 'empowerment' AND 'diabetes'. A separate search with a methodological focus was implemented using the terms 'empowerment' AND 'research'. This search strategy was repeated at a later stage in the research process to ensure relevant material published between 2000 and 2010 was included within the literature review. Selye's seminal work on stress published in the 1950s was accessed manually.

Only articles published in English were considered and studies involving children or adolescents were excluded. A range of literature identified from this search is introduced and discussed below.

2.1 Women and diabetes

To date, little has been written about the lived experience of women whose diabetes is managed with insulin therapy although some literature relating to the lives of women with Type 2 diabetes is emerging from Australia and Canada (Anderson et al., 1995; Koch et al., 1999). The aims of these studies were to contribute to an understanding of the health of women living with a long term condition, providing a greater insight into their worlds and allowing their voices to be heard, with Koch et al. adopting a participatory action research framework. Anderson et al. (1995) focused on how Canadian women managed their condition on a daily basis and considered issues such as the impact of ethnicity and culture on the management of diabetes. The women included in Anderson's studies had either diabetes treated with insulin or were treated with tablet therapy. The

research found that regardless of the type of diabetes, a large proportion of the women sampled were having difficulties in managing their diabetes. Difficulties did not necessarily relate to lack of knowledge, but more to life circumstances such as employment and family commitments. Anderson concluded that diabetes was a multifaceted phenomenon, which needs to be understood in the '*mediating circumstances*' of the women's lives (Anderson et al., 1995, p. 191).

Although this thesis is concerned with women whose diabetes is treated with insulin (as defined in Chapter One) the women may have either Type 1 or Type 2 diabetes), previous research reports are not always so clearly delineated as being focused on either insulin treated or non-insulin treated diabetes. Furthermore, most reports refer to clinical or biomedical diagnoses and/or definitions of diabetes. However, this thesis is concerned, not with medical definitions, but with the experience of living with diabetes and its consequences, and acknowledges that the very nature of being insulin dependent may affect the experience of living with the condition.

Little research in diabetes is gender-specific, and of that which is such as Koch et al. (1999) and Anderson et al. (1995), in many cases the lives of women with diabetes have become '*medicalized*' (Illich, 1975, p. 39). Illich describes health professionals as having '*an even deeper, structurally health-defying effect insofar as they destroy the potential of people to deal with their human weakness, vulnerability and uniqueness in a personal and autonomous way*' (1975, p. 26). He asserts that medicine is a form of social control, concerned with the limitation of power and resources – knowledge could be seen as such a resource. Women are researched by health professionals with a medical interest, and the problems experienced become part of the medical domain; they are taken away from the women themselves and become owned by the health professionals. Language may become more complicated and they may be exposed to a variety of interventions in environments unfamiliar to them.

2.1.1 Diabetes as a long term condition

Diabetes is usually classified as a chronic disease or long term condition. The term '*long term condition*' will be used within this thesis. Strauss et al. (1985) describe factors common to a variety of long term conditions (including diabetes) – managing medical crises, managing regimens, controlling symptoms, reorganising time, managing the course of the illness, living with the social isolation imposed by the illness, normalising life and issues relating to hospital environments and procedures. These could all apply to diabetes. When examining the life-stage transitions of women with long term conditions, White et al. (1992) selected diabetes as the prototype of such conditions, because of its prevalence and the need for significant changes in lifestyle. A key finding for the women researched was that when the demands of life, including the demands of a long term condition were perceived by the women as exceeding their available physical and psychological resources, the result was a disturbance in their psychosocial adjustment to illness, and they viewed the situation as being beyond their control.

Other studies of long term conditions involve women, but not only women.

Packard et al. (1991) suggest that a long term condition may be defined less in terms of its biological characteristics and more by the varied aspects of experience related to illness. Diabetes has been used as an example of a long term condition in other studies e.g. Agrawal and Pandey (1998); Anderson and Bury (1988); Woods and Lewis (1995). Woods, Haberman and Packard (1993, p. 137) considered the demands of long term conditions in women, focusing on diabetes, breast cancer and fibrocystic breast disease. They constructed the notion of '*demands of illness*', extending earlier work on this construct by Packard et al. (1991), identifying 7 domains of illness demands which relate in part to a social model of health. These demands were direct disease effects, disruption of continuity, integrity and normality, social responses, treatment process and patient/provider transactions. The demands of illness were categorised into illness-related demands, personal disruption demands and environmental transactions. When compared

with women with breast cancer or fibrocystic breast disease, women with diabetes reported the greatest number of demands as relating to disease-related demands and environmental transactions. Examples of how these demands of illness may relate to diabetes are outlined below.

- a) ***Disease-related demands*** refer to physical and psychosocial experiences that individuals directly attribute to the disease. In diabetes, examples may be long-term complications or feeling unwell in the short-term due to a low blood glucose level (hypoglycaemia), which in turn may affect an individual's ability to function within their social environment.
- b) ***Personal disruption demands*** are changes in the life course as a result of the disease and may lead to a change in the perception of the self-identity. For example, the individual may experience vulnerability due to the fear of developing long-term complications of diabetes, changes in body image, when the change may be gradual. They may also reflect practical changes to lifestyle that occur as a result of having the disease which may include injections, or changes to timings of meals, an example being the necessity of eating before exercise or going to bed being enforced rather than a choice, in order to avoid hypoglycaemia.
- c) ***Environmental transactions*** according to Packard et al. (1991) are events that occur due to relationships with the social environment such as employment, driving, social networks, and relationships with health professionals. Environmental transactions relate to how the person with a long term condition is positioned within their social context, and how they are perceived by others within that context.

Bury (1982), in his study of rheumatoid arthritis, suggested that long term conditions were biographical disruptions and could be conceptualised as being separate from the self. The disease itself becomes objective and is affected by external sources. However, reported anecdotal subjective experiences of people with diabetes from my experience in

clinical practice suggested that many aspects of life were invaded by following therapeutic regimes, such as relationships and practical issues, making it difficult to separate the disease from the self. Many reported feelings of guilt and blame when things went wrong. They accepted the responsibility, when in fact, external sources may have had a part to play, for example lack of educational opportunities or inappropriate insulin therapy. The feminist disability writer and sufferer of a long term condition Merry Cross, in her preface to Saxton and Howe (1988) writes *'if ever we can't cope, we are blamed for that. We must have done the wrong thing, or eaten the wrong thing, or not done the right thing'*.

The following section is concerned with some of those areas that have been widely researched in diabetes in the medical context of women's health including reproductive functions, sexuality, and eating disorders, although they are also linked to psychosocial aspects of living with diabetes.

Reproduction, diabetes and women

There is a plethora of research which is mainly quantitative in nature relating to women and diabetes in terms of their reproductive functions which include menarche, pregnancy and the menopause (Costacou and Orchard, 2007; Danielson et al., 2005; Holt, 2008; Jedrzejuk and Milewicz, 2005; Kjaer et al., 1992). Discussion and examples of these is necessarily brief, as the emphasis is on blood glucose control and outcomes measurable in medical terms, such as congenital malformations, and long term complications of diabetes. It is recognised that there is a need for this type of research, particularly in terms of preventing future difficulties, but this is not the focus of this thesis.

Women with pre existing Type 1 diabetes form the largest group of women who are pregnant and have a long term condition (CEMACH, 2007; Linn and Bretzel, 1997). There are many studies relating to diabetes and pregnancy. Pre-pregnancy planning is advocated and encourages health-related behaviour such as improvements in diabetes control, genetic counselling, avoidance of teratogenic (medicines which may adversely affect the foetus) medicines, and prevention of neural tube defects. The chances of a

woman with diabetes giving birth to a healthy infant have increased in recent years, as obstetric and neonatal risks have decreased (Garner, 1995). Women with diabetes have a two to three fold increased risk of having a baby with a major congenital malformation, when compared with the general population, and 90–95% of complications during pregnancy are diabetes related, mainly in gestational diabetes (Crowther et al., 2005). The risk of complications is no less for women with Type 2 diabetes if blood glucose control is poor during the early weeks of pregnancy (CEMACH, 2005, 2007; NICE, 2008).

Textbooks relating to the management of diabetes invariably include sections on the management of diabetes during pregnancy (Watkins et al., 1996; Williams and Pickup, 2004). Control of blood glucose during pregnancy is seen as important as an elevation in blood glucose levels may lead to congenital malformations, large babies and stillbirth (London and Gabbe, 1992; CEMACH, 2005). If high blood glucose has occurred during pregnancy, hypoglycaemia may occur in the baby immediately following delivery, as an increased amount of insulin will have been produced to compensate for this.

Although the consequences as a result of pregnancy are considered for both the mother and baby in biomedical terms, there is little consideration of the psychosocial effects for the woman of trying to achieve optimum blood glucose control which is likely to include multiple daily insulin injections, testing of blood glucose levels up to 7 or 8 times a day, frequent clinic visits, nausea and the possibility of hypoglycaemia during the first three months. One study which attempts to redress the balance between quantitative and qualitative research was that undertaken by Berg and Honkasalo (2000) using a qualitative interview method to understand the experiences of 14 pregnant women with diabetes. Here two themes emerged; those of '*objectification*' (Berg and Honkasalo, 2000, p. 41) and '*exaggerated responsibility*' (Berg and Honkasalo, 2000, p. 43). '*Objectification*' referred to a loss of control and an awareness of having an unwell body. A feature of the research was that women depended upon objective measures of their health, particularly in relation to blood glucose levels in order to avoid the risk of an adverse outcome of pregnancy. A second issue was '*exaggerated responsibility*' which included constant

worry, pressure and self-blame and an ongoing concern that something would happen to the unborn child. Berg and Honkasalo's study has not only increased knowledge about the life worlds of these women, but also raised new questions and areas for future research. It also challenged health care professionals involved in caring for pregnant women with diabetes, by providing knowledge from a different perspective – an aim that is central to this thesis.

2.1.2 Sexuality in women with diabetes

Sexuality in women with diabetes is an area in which results from research have often been inconclusive and conflicting. Enzlin et al. (1998) concluded after an extensive review of the literature that there is evidence for sexual problems in women with diabetes and identified a specific pattern of sexual dysfunction in which the arousal phase is especially affected. They concluded that there was a need for further research, particularly in the form of longitudinal studies. Qualitative analysis of data in Shah's (1989) descriptive correlational study of psychosocial adjustment, self-concept and sexual satisfaction of women with diabetes showed that fitting in demands and tiredness were relevant in the way that diabetes affected the lives of women with diabetes. Quantitative analysis showed that increased duration of diabetes was associated with a high level of sexual satisfaction in the same study. However, in contrast, Rockcliffe-Fidler and Kieme's (2003) study of the psychological aspects of sexual function in age-matched samples of women with Type 1 and Type 2 diabetes indicated that women with Type 2 diabetes experienced more difficulties in sexual functioning than women with Type 1 diabetes, and that these difficulties increased with age. Perceptions of body image and the presence of diabetes complications did not seem implicated. However, physical discomfort associated with genitourinary problems; such as thrush infection associated with high blood glucose levels were associated with difficulties in sexual functioning. Recommendations for future research are made for further investigation of the relationship between sexuality and

diabetes. Much research in this area has a medical focus, and this may be an area that would gain from a more psychosocial approach to exploring sexuality and diabetes.

2.1.3 Eating disorders in women with diabetes

Many research studies in the 1980s suggested that eating disorders were more frequent in women with diabetes than among the general population (Hudson et al., 1985; Rodin et al., 1985). However, more recent studies, mainly from the USA, have found fewer differences between women with diabetes and the general population than had been previously suggested. Through research using an experimental design, Grant (1991) reported that women with Type 1 diabetes did not differ from a control group of women without diabetes in terms of body dissatisfaction, disordered eating or psychiatric symptomology. In contrast to this, Levine and Marcus (1997) have argued that subclinical eating disordered attitudes and behaviour may be more prevalent among women with Type 1 diabetes. Whether this is the case or not, for those who have both an eating disorder and diabetes, the combination of the two is a significant problem, as there is also likely to be a detrimental effect on glycaemic control (Friedman et al., 1998).

In an American study Rapaport et al. (1996) suggested that approximately one third of women taking insulin struggle with the eating disorders anorexia nervosa and bulimia with their preoccupations with food, body image, restrictive and/or binge eating, excessive exercise, induced vomiting, and insulin misuse. Depression was often present in conjunction with the eating disorder. Depression in women with diabetes may lead to weight gain, perhaps due to increased food intake and decreased physical activity (Lloyd et al., 1996; Robinson et al., 1988). Robinson et al. (1988) found that depressed women with diabetes had significantly higher body mass indexes (BMI) compared with non-depressed women with diabetes. Lloyd et al. (1996) found that depression was an independent predictor of waist-to-hip ratio (WHR) – a factor indicative of the development of coronary heart disease in women with diabetes, which may be linked to insulin resistance, where an increased amount of insulin is required to have an effect upon the

muscle and fat cells in the body. Women with diabetes are already at increased risk of coronary heart disease and this is compounded by decreased sensitivity to the level of circulating insulin (Huxley et al., 2006).

One way of dealing with unwelcome weight gain may be to manipulate or omit insulin therapy. Polonsky et al. (1994) observed a strong association between insulin omission and eating disorders complicated by diabetes-specific factors such as diabetes-specific distress and fear of gaining weight. Omitting insulin leads to a higher level of blood glucose and therefore weight loss associated with this. There is also a decrease in appetite. Polonsky et al. (1994) suggested that insulin omission was common, not limited to younger women (although there were peaks during adolescence and young adulthood), and that the medical consequences may be severe. Those who omitted insulin were less likely to perform other aspects of self-care. They also had poorer glycaemic control and higher levels of complications and admissions to hospital. Biggs (1993) observed similar associations where a small sample of female insulin withholders was studied. Results indicated that women with diabetes who were preoccupied with eating and weight may become emotionally overwhelmed by diabetes and fearful of a normal blood glucose which may cause weight gain, reinforcing the desire to omit or reduce insulin. This could lead to elevated blood glucose levels and associated weight loss, and a desire not to eat in order to reduce the elevated blood glucose. This may be dangerous, as there is the risk that life threatening diabetic ketoacidosis (DKA) may occur and that the development of long term complications may be accelerated. The Diabetes Control and Complications Trial (DCCT) clearly indicated an increased incidence of complications associated with poor diabetes control (Diabetes Control and Complications Trial Research Group, 1993).

Although not solely concerned with eating disorders, Polonsky et al. (1994) found that those who omitted insulin for weight-related reasons were at the greatest psychological and medical risk in the long term. Specific attitudes including preoccupation with weight and feeling overwhelmed by diabetes were strong predeterminants of

omitting insulin. Findings from the DCCT (1993) suggested that maintaining blood glucose levels to approximate those found in the non-diabetic population may lead to a reduction in the development of complications. However, the use of additional insulin leads to weight gain due to its physiological effects and a resulting increase in appetite. This suggests that while the DCCT results indicated that following a regime leading to optimal glycaemic control significantly reduces the risk of developing long term complications, the goals of the health professional may not be in accordance with those of the women themselves. Studies by Fairburn et al. (1991) and Peveler et al. (1992) suggested that insulin omission does not occur in men, although no reasons were identified. Daneman et al. (1998) proposed a model of eating disturbances in Type 1 diabetes and acknowledged that diabetes pervades most aspects of daily living and suggested that the traditional approach has been to focus on improving glycaemic control, which may worsen the situation. Women within western cultures are susceptible to family, peer and societal pressures in terms of controlling their weight, with often unrealistic portrayal of body weight in the media being presented as the norm, to which many women aspire.

Some studies have adopted a less medicalized approach to eating and dietary behaviour. One such study related to diet, diabetes and male chauvinism (Probert, Maddison and Roland, 1990). Probert et al. reported that men with diabetes were more likely to be accompanied to diabetic support and discussion groups than were women with diabetes, (although the meetings may have been held at times more convenient to women), and that the wife of a man with diabetes prepares and adopts his diet, whereas the husband of a woman with diabetes does not. These findings were reinforced in Hepworth's (1999) study, where it was suggested that women maintain food provision in order to meet men's preferences.

2.1.4 Multiple roles

Many women, with or without long term conditions, fulfil multiple roles in midlife (Napholz, 2000; Reid and Hardy, 1999). These are primarily a combination of work and

family related roles. They may fulfil a positive function in women's lives, but if an imbalance between them occurs, they may become a source of overload and conflict, even though they may be necessary in financial or economic terms. Role overload and role conflict are two potential outcomes of fulfilling multiple roles (Barnett and Baruch, 1985), but this may also depend upon the value and worth attached to those roles by both society and the woman herself. Role overload refers to the situation where too many demands are placed on the woman to enable her to fulfil them all satisfactorily, whereas role conflict is defined as when the demands from two or more roles means that performing one role well means that the other(s) will be performed less well. Role stress occurs when roles are difficult, conflicting, or have unrealistic goals associated with them. Barnett and Baruch's study of women aged 35–55 who were not diagnosed with a long term condition demonstrated moderate levels of overload and conflict. It was the role of parent that was a major source of stress in these middle years, rather than that of paid worker. Negative perceptions of roles were influenced by the perceived quality of the role undertaken. These findings are pertinent to the experience of women with long term conditions, as they also have a health related role to undertake in addition to the self-care behaviours required to maintain health.

The latter point has been highlighted in a recent comparative quantitative US study (Coty and Wallston, 2008). In this study women with rheumatoid arthritis experienced lower levels of well being in relation to role stress and imbalance compared to those without a long term condition. Those women with more roles experienced increased levels of role stress and a decreased sense of role balance. In the same study, the greater the illness severity, the more role stress and less role balance was experienced, leading to lower levels of psychological well being. Plach et al. (2004) demonstrated that women with rheumatoid arthritis were able to improve role related experience by discarding roles that were in conflict with the symptoms of their condition, such as pain and fatigue, where it was difficult to fulfil their social roles during acute exacerbations of the condition. However, this was associated with guilt and low self

esteem, particularly as they often focussed on the needs of others rather than themselves.

Wuest (2000) has referred to strategies used in relation to roles in her feminist grounded theory study of women's caring patterns. Some of these strategies are relevant to women living with diabetes, who need to also attend to their own self-care needs. Such strategies include anticipating events and developing routines to deal with the needs of other family members and also themselves, such as making sure that food is ready for the family, and then injecting insulin at the appropriate time. At times, sequencing events in order of priority will be necessary, and the needs of managing diabetes will take precedence over the needs of others, during a hypoglycaemic attack for example. Repatterning refers to reducing or overcoming the negative effects of role demands, and relinquishing refers to giving up negative roles and replacing them with others that meet the needs of the women, which gives a greater sense of control over the situation. In the case of diabetes, this may mean adjusting working hours from full-time to part-time, if a symptom of diabetes is fatigue. These changes may not necessarily be planned, and combining strategies so that several demands are met simultaneously, some at the expense of others, demonstrates the resilience of the women in juggling available resources. Kralik (2002) conducted a qualitative study with storied correspondence as a data collection method in women aged 30–50 with a variety of long term conditions, including diabetes. Findings suggested that there was an initial period of turmoil and distress immediately following diagnosis. Kralik defines this as '*extraordinariness*' (p. 147) linked to a feeling of loss of control. This was followed by a phase where the condition was incorporated into their ordinary lives '*ordinariness*' (p. 147), similar to that of normalisation discussed in Section 2.2.1 of this chapter. Both extraordinariness and ordinariness were linked to the social context in which the women lived and the cultural expectations within that context that the needs of others should be placed before their own. However, this was not necessarily a single linear process, and transitions occurred

between the two phases throughout life, particularly in the presence of adverse events such as hypo or hyperglycaemia in the case of diabetes.

2.2 Stress and diabetes

2.2.1 Stress as a concept

Stress is an important concept in relation to this thesis, as stress is central to the focus of two of the three research questions identified in Chapter One. Here the literature review is divided into biomedical and psychosocial aspects of stress. Although this thesis does not have a biomedical approach as its main focus, the physiological outcomes of stress have the potential to affect blood glucose control, and the symptoms may also resemble those of hypoglycaemia. Both of these outcomes have the potential to affect psychosocial aspects of daily living with diabetes, not least because of the importance placed on avoiding poor control and the burden this places on people with diabetes. Psychosocial aspects of stress are considered in relation to daily hassles and life events. Models of stress will be reviewed, and the relationship between stress and diabetes examined.

To my knowledge there have been no previous qualitative studies *specifically examining the experience of stress and diabetes in women in midlife* – although there have been some relating to women and diabetes and psychosocial issues, across both types of diabetes (Anderson et al., 1995; Hepworth, 1999; Koch et al., 1999; Kralik et al., 2000; Kralik, 2002). Such studies have been discussed in Section 2.1 of this literature review relating to women and diabetes. Studies relating to the examination of stress in women with diabetes using mainly quantitative methods will be discussed as part of this current section. The process of writing this review has indicated that stress is a complex phenomenon and invades many areas of experience.

Stress is a complex concept to define as it depends upon the subjective experience of each individual and crosses many interdisciplinary boundaries such as medicine, psychology, sociology, and epidemiology. As disciplines view it from different perspectives

and in different ways, as indeed do individuals who are experiencing stress, there is no single definition that is universally accepted; if indeed stress is accepted as a concept at all. Biomedical and psychosocial models are explored in the following sections, as the two are interrelated.

During his pioneering research on stress, in which he observed enlargement of the adrenal glands, intestinal ulcers and atrophy of the immune system in response to stress in rodents, Selye (1956) extrapolated that similar non-specific symptoms were present in people with a variety of differing medical conditions. This observation led to the development of the General Adaptation Theory (GAT) or General Adaptation Syndrome (GAS), which, according to Selye, affects virtually every organ and chemical constituent of the human body. One of Selye's supporters was Frederick Banting, one of the co-discoverers of insulin. Selye's initial research was involved with inducing the stress response by means of injecting foreign substances into rats including formalin, tissue extracts, hormones and insulin, or exposing them to environmental factors such as temperature changes, exercise, x-rays, pain. He concluded that the GAS was an alarm reaction and affected three systems of the body – adrenal, thymicolymphatic (including the thymus gland, spleen, lymphatic tissues) and intestinal system. This had the effect of stimulating the nervous system and the endocrine glands, especially the pituitary and adrenals to produce adaptive hormones. The three stages were alarm, resistance and exhaustion. A generalised reaction resulted regardless of the nature of the stimulus, a stress response evolved from the interaction of an individual with an environmental (either internal or external) stimulus. The term 'stressor' is applied to the agent inducing stress, and 'stress' refers to the resulting condition. Although this theory only takes physical stimuli into account, and not psychosocial factors such as the context of stress or personal traits, Selye's ideas remain central to an understanding of the stress response.

The term 'stress' was coined from engineering terminology – the concept of engineering stress was applied to biological stress. Although stress was complex and abstract Selye argued that it existed, albeit not independently – it was experienced by

someone and manifested as a reaction to the action of an agent (or stressor). He described the stress response as having a tripartite mechanism:

- 1 *Direct effect of the stressor on the body*
- 2 *Internal responses which stimulate tissue defence*
- 3 *Internal responses, which stimulate tissue, surrender by inhibiting defence.*

(Selye, 1956, p. 47)

Selye asserted that these mechanisms need to be in balance for resistance and adaptation to stress to occur; otherwise diseases of adaptation may result, where the body is unable to produce an adequate adaptive response. Indeed, he described stress as a disease of adaptation.

In contrast, Kasl (1995) described five aspects of stress:

- a) It is an environmental condition, objectively defined and measured
- b) It is a subjective appraisal or perception of an objective environmental condition
- c) It is a particular response or reaction, such as a physiological response or medical symptoms
- d) it links environmental characteristics with personal characteristics and. there may be a misfit between the two
- e) it is a process that cannot be reduced to stimulus-response or cause-effect.

Parts of this description concur with that of Selye, but other elements are introduced such as subjectivity, personal characteristics, and environment. These additional aspects of stress are encompassed in the description of stress offered by Cohen, Kessler and Underwood (1995) who have suggested that there are three distinct models of stress – epidemiological, biological and psychological. The *epidemiological* model is concerned with identifying environmental variables that may adversely affect health; the *biological* model concentrates on physiological reactions that may have a deleterious effect on health; the *psychological* model is concerned with the environmental exposure, the individual's

response and the mediating effects of these. However, the approaches have the potential for overlap, rather than existing independently. Stressors may be viewed differently in different contexts – described by Levi (1995) as the '*spice of life*' or '*kiss of death*'. They may be viewed as a welcome challenge or an insurmountable problem, depending on individual perception at a given time.

The current study is not concerned with measuring physiological responses to stress, but with women's perceptions of what stress means to them in the context of their own experience. There can be no single definition of stress, as it is defined from the perspective of the individual's experience, within a specific social context.

Stress is usually defined by the visible response, rather than by the contributory factors, which may be internal such as individual perceptions, or external such as physical trauma. It often occurs as a result of a misfit between the individual and their internal or external environment, whether physical or psychosocial, and the label of 'stress' is applied to a set of signs and symptoms, without looking at what it means to each individual. It is therefore perhaps not useful to search for a definition of stress, but to look at what distresses people in terms of their own perceptions.

Given the problems in defining stress and its diversity, it follows that stress may be difficult to measure. Indeed Selye (1956) acknowledged that no one measurement of stress can be conclusive in itself. The intention may be to measure the stress itself, but what is actually measured is the response to it, be it physiological including neuroendocrine function, cardiovascular response, immune function or emotional, such as depression or anxiety. Sometimes it is the contributory factor that is measured which may be a life event or daily hassle. In fact, part of the stress process is measured rather than the stress itself.

Stress can be described as response to a stimulus, which may not necessarily be negative, but proactive and positive in nature and Levi (1995) suggested three types of responses to stress – emotional, behavioural and physiological.

Emotional -The emotional response to stress may manifest as anxiety, and at its most severe, as Post Traumatic Stress Disorder (PTSD). This disorder is often diagnosed following exposure to, and survival of, a traumatic event which may be experienced in a war situation or during accidents. Using people's initial responses to the symptoms of acute myocardial infarction, Alonzo (2000) discussed PTSD as a consequence of developing a chronic disorder and as affecting patterns of coping behaviour, and stated that the principles may be applied to other chronic diseases. He surmised that individuals may '*experience a continuum of cumulative, traumatic events associated with chronic disease and other life course events*' (p. 1476). The onset of diabetes could be perceived as such a life course event. Alonzo envisages a continuum, with full-blown PTSD with its related symptomology at one end, to more benign anxiety reactions at the other. He suggested that if people move from the more benign symptoms to PTSD, they become not only less able to deal with the course of their disease, but also other life events. In diabetes, maladaptive coping in performing aspects of diabetes self-management may be manifested as non-attendance at clinic appointments, or not following their recommended therapeutic regimen, for example following a low fat diet, exercising and insulin administration. This may be due to the initial experience of the disease which has the potential to produce a continuum of traumatic responses. This is at odds with the concept of '*normalisation*' as an explanation for behaviour during long term conditions (Royer, 1998), which is discussed later in this section.

From a review of literature relating to PTSD Alonzo produced a list of factors which may link long term conditions to PTSD (2000, p. 1477). These factors are identified below and, for the purpose of this thesis, have been related to diabetes:

- Physical – sudden onset; lack of preparation; threat to life and traumatic loss as in the case of diagnosis with diabetes.
- Psychosocial – collapse of the structure of the self; hindrance to continuous autonomous functioning; loss of wholeness, integrity or a way of life; inability to

integrate the experience into the self-structure, such as a change in an individual's self-perception and a potential sense of loss of perceived good health.

- Other psychosocial factors relating specifically to diabetes that could be added may include those relating to the individual's social interactions e.g. eating out, driving, employment, and travel.

Shalev et al. (1993) stated that PTSD should be classified as a psychiatric disorder that may result from reaction to illness rather than from the other typical stressors of trauma-related events and incidents. PTSD is characterized by three categories of symptoms that last at least one month (p. 247) – repeatedly reliving the traumatic event, avoidance of cues reminding the patient of the event with a numbing of general responsiveness, and increased arousal such as in the case of a severe hypoglycaemic attack.

In contrast, Scott and Strading (1994) have described the concept of Prolonged Duress Stress Disorder (PDSD) which they define as a type of stress that people with prolonged disease may experience. Diseases that it is associated with are those which are painful, demanding, engulfing and fatal, and have a sudden unexpected onset or associated event – all of which have the potential to apply to diabetes, although it is not specifically referred to by Scott and Strading. Medical experiences become triggers and exert a cumulative effect when added to other factors in daily life. It could be argued that this is a cyclical process. Life events may affect how people cope with other stressful experiences related to long term conditions, as indeed long term conditions may affect how people cope with life events.

Factors that the onset of illness such as diabetes may have in common with a sudden traumatic event may be sudden onset, a sense of lack of control by the person affected and a perceived or actual threat to life. Symptoms and behaviour suggestive of PTSD in medical patients include either preoccupation with the illness, or denying its consequence. This may be manifested as overlooking limitations imposed by the illness and engaging in life-threatening behaviour and/or avoiding medical care – behaviour that

may be observed in those with diabetes and may be described as self-destructive behaviour (Rubin and Peyrot, 1992). However, Royer (1998, p. 101) described such behaviour as '*normalisation*', rather than such behaviour being maladaptive or non-compliant, as it is often regarded by health care professionals. She referred to it being a survival tactic for those for whom being a patient is a small part of their lives, when compared with being a person. What is viewed as maladaptive may in fact be a positive choice to reject one lifestyle in favour of another. It is possible to do this in diabetes as it is often a hidden disease, with no visible symptoms, unless things go wrong. Behaviour occurs with a view to being defined as normal by the societal context and culture in which one lives and may include disrupted eating patterns, hiding insulin equipment, or avoidance of carrying glucose tablets to prevent making an individual feel different. The terms '*coping*' and '*adaptation*' are often used in connection with a chronic disease and Royer distinguished between the two, as well as introducing normalisation. She stated that '*coping is the special mobilisation of effort and the drawing upon unused resources or potential, and always involves some type of stress*' (p. 81) – that is it may relieve the symptoms of stress, but not necessarily the cause or situation. Of course, if the cause is diabetes itself, it will not be possible to remove it.

Royer defined normalisation as '*the processes a chronically ill person uses to continue what that person perceives to be a normal life*' (p. 102). The definition of personal goals and values in life will influence what that life role is. These processes may not coincide with the behaviour required to follow the treatment recommendations of health care professionals; indeed the attitude of the professionals concerned may in itself become a stressor capable of inducing guilt. As there may be a desire to function in a certain social role, goals and expectations may require readjustment. In the case of diabetes this may involve redefining the biomedical limits imposed by health care professionals in relation to acceptable blood glucose levels to allow functioning in daily life. A degree of conflict and alienation between the health care professional and the person with diabetes may result. The outcome of normalisation may be to maintain a

sense of the self that existed prior to the onset of illness and maintain a feeling of being in control, rather than allowing the disease to cause a sense of biographical disruption (Bury, 1982), illustrating the difference between being 'a diabetic' and a woman with diabetes. Normalisation may also have the goal of avoiding stigma, to avoid social isolation, not to be seen as different from other people.

Normalisation involves both cognitive and behavioural components and may involve redefining what constitutes normality. Behavioural components consist of carrying on as normal in employment, running a household or fulfilling roles as wife, mother and carer. This allows the affected individual, as well as others, to view themselves as normal if they so wish – in the case of diabetes as not having the disease, in an effort to preserve a preferred self-image. This is likely to require effort. Royer (1998) described energy-conserving behaviour as '*pacing*' (p. 125). This consists of balancing daily activities with medical regimes. This is a personal activity and a social process involving negotiation, which everyone does to some extent. In diabetes, an example of pacing could be 'cheating' on a diet one day and overcompensating the next – in a similar way to people who are following a diet for weight loss purposes. The loss of predictability, for example in the case of hypoglycaemia, means that there is an inability to plan for all eventualities, and this may cause anxiety. This may involve the avoidance of potentially embarrassing situations in public places such as eating out and/or withholding information in the workplace. This strategy would allow the person with diabetes, as well as others, to perceive themselves as normal, in contrast to the loss of spontaneity and the need to always plan.

Cognitive strategies of normalisation are concerned with minimising struggles and adjustments and playing down the consequences of this, an example being the development of long-term complications of diabetes which may require adjustments in daily life. Optimising the situation is another way of normalising situations, with the philosophy that things could be worse, and avoidance of portraying the self as a victim. This is when social comparisons are made with others who may be perceived as being in

a worse position than them, priorities, values and beliefs are adjusted accordingly. Validating personal experiences is a function of support groups such as Diabetes UK. However, many people with long term conditions choose not to attend such groups as they wish to avoid being frequently reminded of the permanence of their condition. Lack of time may also be a barrier to attending such groups. Other cognitive strategies of normalisation involve acknowledging positive personal characteristics within themselves such as determination, courage, tenacity and denial of the severity of the illness or denial of the potential of the development of life-threatening diabetic ketoacidosis or long-term complications. Although denial is often viewed as a defence mechanism with negative connotations, this may be called into question if it allows an individual to function in difficult circumstances. These strategies may be used interchangeably, at a conscious or unconscious level, to avoid the potential social isolation that could be imposed by living with a long term condition.

2.2.2 Stress stimuli

It has already been stated that stress may be due to an imbalance between demands and the body's response to these demands. The demands may be physiological, psychosocial or environmental and they may be discrete or overlapping. The stimulus and response to demands is likely to differ between individuals. Selye (1956, p. vii) referred to the individual as a mediating factor – *'the same stress which makes one person sick can be an invigorating experience for another'*.

Stressful stimuli may be categorized as follows:

- a) **External** examples of these may be social pressures, family problems, life events, daily hassles. Linked to these external factors Levi (1995) suggested that a cause of stress may be role conflict. This would seem to be particularly relevant to modern women with diabetes who often also fulfil multiple roles of wife, mother,

carer for elderly dependents and employee, to name but a few. Stressors related to this may include excessive demands, unsatisfied needs and unmet expectations.

- b) **Internal** examples of these may include personality which may be susceptible to stressful stimuli, emotions, health beliefs and perceptions of control. An example of internal factors has been shown by Stabler et al. (1987) who exposed children and adolescents with diabetes to a stressor in the form of a video game. Those who were classified as having Type A personality traits such as being competitive and impatient demonstrated a rise in blood glucose levels in response to stressful stimuli, whereas those who demonstrated a Type B personality traits such as being more patient and relaxed showed a reduction in blood glucose levels. Those who have Type A personality traits have been shown to be more autonomically reactive and show larger physiological changes in reaction to stressors than those who have more Type B personality in the general population (Friedman and Rosenman, 1959).

External stimuli may also be categorised as presenting as daily hassles and uplifts or they may be perceived as discrete or long term difficulties. Daily hassles are usually defined as being smaller events than life events or less stressful discrete events which occur more frequently or on a more regular basis (Kanner et al., 1981). The effects of daily hassles and uplifts (pleasant events) on stress were acknowledged by Selye (1956, p. vii) when he stated that *'crossing a busy intersection, exposure to a draft, or even sheer joy are enough to activate the body's stress mechanism to some extent'*.

Kanner et al. (1981, p. 3) defined hassles as *'irritating, frustrating, distressing demands that to some extent characterise everyday transactions with the environment. They include annoying practical problems such as losing things or traffic jams and fortuitous occurrences such as inclement weather, as well as arguments, disappointments, and financial and family concerns.'*

One of the most well known measures of stress was developed in the 1960s by Holmes and Rahe – Social Readjustment Rating Scale (SRRSQ) (Holmes and Rahe, 1967). The scale was devised to give some measure of the importance of social events that require a person to make an adjustment and may be implicated in the onset of disease. The aim was to provide a quantifiable research tool for epidemiological studies of disease, looking at the relationship of biological, psychological and sociological factors to health and disease. Holmes and Rahe acknowledged that different events might require a range of times in order to adjust or come to terms with the event. Their research included asking 400 people from diverse backgrounds to rate 43 life events in terms of the intensity of the readjustment and the length of time required to readjust – a subjective quantification of the statements. Events included those related to family, employment, relationships, education, leisure, health, financial status.

Of course, life events may be perceived in different ways by individuals – *'People react to their "life situations" or social conditions in terms of the meaning of those situations to them'* (Hinkle, 1974, p. 356). Indeed, many of the events on the SRRSQ scale could be interpreted as being either positive or negative. However, the theme common to them all was that they were associated with the need for adaptive or coping behaviour. The scale generated consisted of a list of life events hierarchically arranged according to the amount of life change and readjustment necessary. It is scored according to the life event experienced, and then compared with physiological and psychological tests, for example measurement of psychological well being. The SRRSQ has been subject to some criticism in terms of outcome criteria and the fact that the scale relies on retrospective data that has been subjectively recalled, and modifications have been made to the instrument when used in subsequent studies (Bradley, 1979; Stenstrom et al., 1993). Holmes and Rahe (1967) proposed that the readjustment required by major life changes substantially increases the risk of developing physical illness and that life events are significantly associated with psychological disturbance and the presence of physical disease. This may be at the onset or during exacerbation of an illness or

fluctuations in symptoms. However it is questionable whether the event (which could be the physical illness itself) or the consequences of the event are responsible, in physiological, psychological or social terms. Furthermore the less serious hassles and uplifts are not included in the scale.

Hassles, life events and uplifts may all be interrelated. In their study of the comparison of two modes of stress measurement, daily hassles and uplifts versus major life events, Kanner et al. (1981) concluded that the measurement of daily hassles and uplifts may be a better approach to the prediction of adaptational outcomes than the life events approach. They compared a 117 item Hassles Scale with a 135 item Uplifts Scale and a life events scale with two measures of psychological wellbeing. Kanner and his co-authors concluded that daily hassles provided a better estimate of life stress than major life events and were better predictors of psychological symptoms. Perceptions of what constituted hassles and uplifts varied between different individuals and groups of people, for example in students, compared with middle-aged people and health professionals. Hassles and uplifts were studied together by Kanner et al., as positive experiences may also have an impact, indicating that one may offset the other, or have a stronger effect. Uplifts are counterparts to hassles and perhaps act as breathing spaces from the stress of hassles and life events or may counteract the effects of negative stressors. In women but not in men, Kanner (1981) found that uplifts were positively correlated to psychological symptoms. Tentative explanations for this included gender-related values affecting the perceived significance of stress, gender differences in coping, and differences in situational contexts between men and women. Kanner et al. (1981, p. 6) asserted that negative stress in the form of hassles caused physiological changes that may be harmful, and that positive experiences in the form of uplifts may have served as '*emotional buffers*' against stress disorders. In relation to women living with diabetes, examples of hassles may be having to eat when not feeling hungry or testing blood glucose levels on a regular basis. Hassles not related to diabetes might also impact on blood glucose levels. Uplifts

could be related to feeling well, or coping with a social event, with the absence of hypoglycaemia.

Hinkle (1974) also suggested that there was a relationship between daily hassles and life events, as life events may be influenced by daily activities in terms of relationships and health-related behaviour. Kaplan (1979) agreed that daily hassles may disrupt coping processes and might differ in terms of their perceived meanings for individuals. Similarly Kanner et al. (1981, p. 4) suggested that hassles may function as '*critical event mediators*' of life events. The life event may create a situation, but the daily hassle or uplift is more prominent in terms of effect. Hassles may also function independently of life events, depending upon an individual's social context, for example they may have a cumulative effect as a result of repetition, or alternatively they may occur rarely.

Studies of life events and daily hassles and uplifts as described above, suggest that each may affect the experience of stress independently, or there may be an interaction between them. Other factors of relevance are the psychosocial context within which they occur, and the individual perception of their importance.

2.2.3 Stress and diabetes

Stress has been associated with the onset of diabetes since the 17th century when Thomas Willis stated that diabetes was related to '*prolonged sorrow*' (1684, p. 74). Some research has supported the theory that stress may increase the chance of developing diabetes. For example, Robinson and Fuller (1985) showed in their qualitative study that people with diabetes were more likely to have suffered a major family loss prior to the onset of symptoms. Studies of this type have been criticized (Surwit et al., 1992) for relying on specific life events being recalled. However, the recall bias is likely to be low for such a major life event. It has been suggested that stress may affect the onset of the

disease by directly or indirectly triggering an auto immune response which leads to the destruction of the insulin producing cells within the pancreas (Atkinson and Eisenbarth, 2001).

Studies related to stress and diabetes can be broadly defined as falling into two categories, those that examine the direct effect of stress on blood glucose control, and research on the relationship between stress and diabetes self-care behaviours.

Studies examining the direct effect of stress on blood glucose control

In terms of the impact of stress on diabetes, one potential indicator is the measure of glycaemic control – (glycosylated haemoglobin which measures the average blood glucose level in the preceding three months), as stress has a physiological effect on blood glucose levels. However, this measures the average level of blood glucose during the previous three months and will not reflect short-term fluctuations in blood glucose levels. Any true measure of stress, if it exists, would need to be specific to each individual – one way of achieving this is to allow respondents to define their own stress, which this current thesis does.

It might be expected that there would be a relationship between stress and an increased level of blood glucose, but the relationship between the two is far from clear, and it is a complex area of research. Psychological stress is frequently associated with physiological changes within the nervous and hormonal systems and many hormones have been shown to affect carbohydrate metabolism and blood glucose levels (Williams and Pickup, 2004). However, there has been variation within the measurement tools utilised in these studies, in both quantitative and qualitative terms. The role of other variables in moderating or mediating the impact of stress on diabetes control is also unclear. Other limitations lie with the perception and definition of stress by individuals, as the context within which stress may occur may affect how it is experienced and reported.

Although acute stress appears to cause destabilization, the glycaemic changes may occur in either direction, leading to a raising or lowering of blood glucose levels (Lustman et al., 1981).

Diverse results have been obtained from many different studies and the literature is, at times, contradictory in relation to the effect of stress on blood glucose control (Aikens et al., 1994; Cox et al., 1984; Lloyd and Orchard, 1999; Lloyd et al., 2005; Lustman et al., 1981; Stenstrom et al., 1993; Surwit and Schneider, 1993; Surwit et al., 1992). Some of these studies have been laboratory based, and others have been undertaken outside of laboratories and been more observational in nature. Some laboratory studies have been conducted to demonstrate the effects of specific stressful situations on blood glucose levels and have reported that blood glucose levels become unstable following these stimuli (Goetsch et al., 1993). Early experiments in stress and diabetes were performed in the 1950s and 1960s (Hinkle and Wolf, 1952; Vandenberg et al., 1967) which often showed an unexpected reduction in blood glucose levels when stressful stimuli were applied. Surwit et al. (1992) suggested that the effect of stress on blood glucose levels may be due to variations in autonomic nervous system status perhaps due to diabetic neuropathy (damage to the small blood vessels supplying the nerves), existing stress levels or personality types. Also what one person perceives as a stressor, another may not. It may be difficult to identify the exact stressors and how they are perceived by the individuals themselves and the exact mechanism by which major life events adversely affect diabetes is unclear. Lloyd et al. (1999) carried out a study to examine the relationship between stressful life events and alterations in glycaemic control among adults with Type 1 diabetes who were consecutive outpatient clinic attendees, using the Life Events and Difficulties Scale (LEDS) (Brown and Harris, 1989). The LEDS is a semi-structured tape-recorded interview that measures the occurrence of stressful life events during the previous year – a specified period in Lloyd's study, although events occurring further back can also be measured with a degree of accuracy. Stressors were defined as life events (defined as a life change likely to be followed by a strong emotional

response) and long-term difficulties (defined as a problem that lasts 4 weeks or longer. Specific types of life events were observed, including severe personal stressor events (defined as any life event or difficulty involving severe interpersonal conflict, disturbed behaviour or death of a close tie) and positive events (defined as any life event characterised by a degree of positivity) (Lloyd et al., 1999, p. 1279). Lloyd et al. concluded that recent stressful experiences were significantly associated with alterations in blood glucose levels, with negative stressors being associated with worsening blood glucose control. Life events and difficulties occurring less recently did not appear to have an impact. Lloyd et al. acknowledged that the group of subjects was not necessarily representative of the whole clinic population and indeed of all people with diabetes, as only people with Type 1 diabetes who were complication-free were included. Life events and difficulties associated with diabetes were excluded from Lloyd's study, stressors, in contrast to this current thesis.

Much of the previous research has taken a very biomedical view of stress (Aikens et al., 1994; Cox et al., 1984; Lloyd and Orchard, 1999; Lloyd et al., 2005; Lustman et al., 1981; Stenstrom et al., 1993; Surwit and Schneider, 1993; Surwit et al., 1992), with a strong focus on blood glucose levels, which this study does not do. An overarching finding of such research has been that increases in blood glucose levels are generally associated with negative life events and decreases in blood glucose control with positive life events (Cox et al., 1984; Lloyd and Orchard, 1999). For example Cox et al's study (1984) reported a significant positive correlation between glycosylated haemoglobin levels and daily hassles in adults with Type 1 diabetes, in that blood glucose levels were increased. In this study neither following a therapeutic regimen nor having social support correlated with blood glucose levels. Respondents felt that hassles and uplifts affected blood glucose in different ways – uplifts reduced blood glucose and negative stressors increased blood glucose levels, which supports Lloyd's work. Using a daily hassles scale, Aikens et al. (1994) analysed women's glycaemic responses to everyday life stress and explored the role of coping resources as potential stress moderators. The internality of diabetes (a

belief that outcomes are within one's control) and self esteem was assessed among 25 women with Type 1 diabetes who monitored daily stress levels and blood glucose for 30 days. Aikens found an association between blood glucose levels measured on the same day as the stress occurred, but not on the previous or the next day. Blood glucose was found to be higher on more stressful days and personal characteristics did not explain the differences in the association between stress and glucose. However, some women responded more highly to stress than others. There may be physiological or psychosocial explanations for these differences. Although the responses to stress appear to be short term, that is not to say there may not be a cumulative effect in terms of the development of long term complications.

Stenstrom et al. (1993) have also carried out a study into recent life events, gender and diabetic control in people with Type 1 diabetes. Stress was measured using life event and social support questionnaires. The life event questionnaire was based upon the SRRSQ of Holmes and Rahe (1967) and was self-administered. The presence or absence of life-change events in work, finances, personal and family areas over the past year was recorded. The main difference between this and the original SRRSQ was that respondents were asked to identify whether events were positive or negative in nature, an important distinction as identified in Lloyd et al's (1999) work. Glycosylated haemoglobin was used to measure change in blood glucose levels. Men who reported mainly negative life events showed poorer control than those reporting few negative life events or none. There was also a lack of positive events reported among the men. In contrast, in women, the more events reported, especially positive ones, the better the improvement in metabolic control, suggesting a cumulative impact of such events. These results suggest that life events may be significant to diabetic control, but that the genders need to be considered separately. There was no appreciable difference between men and women with regard to what was defined as a negative or positive event. Social support questionnaires were a feature of Stenstrom's (1993) study and are worthy of mention. The social support questionnaires measured both qualitative and quantitative aspects of

social support such as from family and relatives, friends, workers, using a modified version of the SRRQ and a 7 point social support questionnaire. Findings suggested that the men with poorer glycaemic control and a high number of negative life events had a poorer social network than the comparable group of women, suggesting that social networks may have a mediating effect upon the impact of stress upon blood glucose control.

With the exception of Stenstrom et al. (1993), the studies critiqued in this section have utilised objective measures of the effect of stress on blood glucose control. However, qualitative, subjective assessment of stress as a socially constructed phenomenon can also be an important research finding in itself, and this will be considered in this thesis.

Research on the relationship between stress and self care

In terms of the relationship between stress and self-care behaviour, it is not clear whether it is the physiological effect of the stressful event which precipitates changes in diabetes control or whether changes in self-management behaviour as a reaction to stressors might be more important. Stress may directly affect control through changes in hormonal activity – the biomedical approach. Stress may indirectly affect glycaemic control by disrupting self-care routines that influence glycaemic control – this is known as the behavioural approach. It would appear that personal, emotional, behavioural and metabolic factors are interlinked. Studies have shown that there are gender differences in outcomes of self- management of diabetes, in that men achieve more consistency with dietary and exercise behaviours and receive greater social support for making lifestyle changes (Fekete, 2007; Probert et al., 1990). Furthermore, research suggests that men also have better outcomes within diabetes related issues such as daily hassles and anxiety (Connell, 1991; Fitzgerald et al., 1995; Rubin and Peyrot, 1998).

Peyrot et al's international cross sectional qualitative study (2005) found that 41% of patients had poor psychological well being, and diet and exercise self-care behaviours

in particular were affected by psychological problems. Although approximately half of the samples were female, the findings are not gender-specific. Metsch et al. (1995) studied the relationship between psychological distress, diabetes-related health behaviour and level of glycosylated haemoglobin in people with Type 1 diabetes. The findings included the fact that depression was evident only in women, who also exhibited more anxiety than men. This gender difference in psychological morbidity has also been observed in other studies (Lloyd et al., 2000; Lloyd et al., 2002). Poorer glycaemic control was found to be related to depression and Metsch et al. (1995) assumed that the relationship between depression and the level of blood glucose may be due to changes in diabetes-related health care behaviour. Depression is associated with lower levels of physical activity and poor diet, which may go some way to explaining the relationship between depression and higher glycosylated haemoglobin. Patients who check their blood glucose levels frequently have been found to have a significantly lower level of glycosylated haemoglobin (i.e. better diabetic control) than those who check less frequently (Lloyd et al., 2002). However, depressed individuals also attend more medical consultations than non-depressed ones, which may have implications for self-care (Lloyd et al., 2000). Konen et al's study of people with Type 1 and 2 diabetes (1993) has suggested that behaviour may be influenced by individuals' perceptions of stress, coping and family function and may be further modulated by beliefs about whether they were able to control the occurrence and cause of the illness. Aikens et al. (1992) in their study of people with Type 1 diabetes have suggested that following a diabetes regimen may not mediate the relationship between stress and control, suggesting that the direct effects of stress on diabetes might be more important. Indeed, Lloyd et al. (1999) did not observe any significant association between changes in glycaemic control and diabetes self-care, suggesting that the association between glycaemic control and behaviour is a complex one. All of these studies suggest that there is a relationship between the levels of stress and self-care, but that the relationship is not straightforward. This thesis is concerned

with exploring the intricacy of the relationship between stress and diabetes, particularly in relation to the need to incorporate an insulin-based therapeutic regimen into the patterns of daily life.

The implications for practice are also complex as interventions to reduce stress will differ, depending upon which mechanism is being employed. If the stress mechanism is physiological, interventions that directly reduce stress will be useful such as biofeedback or relaxation training. If the mechanism is behavioural, interventions aimed at behaviour change will be of more use (Lloyd et al., 2005). However, it may be difficult to separate the two mechanisms, as a physiological response may impact upon subsequent behaviour. An example of this may be a feeling of lethargy when stress levels are high, leading to a lack of motivation to engage fully with a therapeutic regime. Conversely, events in daily life may impact upon the management of diabetes, an example being lack of time to exercise, which may in turn impact upon blood glucose levels.

In summary, it is generally accepted that high levels of stress are associated with changes in glycaemic control in adults, although the mechanisms through which this occurs remain unclear. There may be an impact on self-care behaviour when stress is present, and stress may also have a direct effect on diabetic control. Stress may be viewed as a disempowering concept as the effects can be viewed by some people as interfering with their ability to be in control, and this is at odds with the concept of empowerment which is a key component within the recommendations for care of people with diabetes (DOH, 2001). As previously discussed in this chapter, poor glycaemic control may be an outcome of living with stress and diabetes. A focus on glycaemic control is central to consultations between women with diabetes and health care professionals. If glycaemic control is not seen to be within prescribed biomedical limits, women may feel disempowered within relationships and during consultations with health care practitioners, who may be viewed as being in positions of power. The notion of '*compliance*' is a common model in prescribed patterns of care.

'*Compliance*' refers to conformity to medical goals to which there is an expectation that the patient will adhere. It is a restrictive medical model of behaviour based on the supremacy of medical knowledge and power, and is a term that is in decline in diabetes care, although the women's described experiences in my own clinical practice strongly suggested its existence remains in practice. In a review of existing research Lutfey and Wishner (1999) suggest characteristics of noncompliance as being related to demographic, psychological, behaviour and personality characteristics, health beliefs, social context and practitioner/patient communication. The term '*noncompliance*' firmly sets the blame for what is regarded in medical terms as poor glycaemic control on the patient, and modification of behaviour is seen as a desirable outcome by the health care professional. The action that is in fact being taken (or not as the case may be), is often not seen by professionals as a deliberate decision, based on very good reasons. However, it is more often seen as a failure, rather than as an adaptation to living with diabetes in a way that is acceptable to the person concerned. The danger is that this negative judgmental view is then projected onto and internalised by the individual concerned. The person is given the responsibility of managing their diabetes on a daily basis, but not necessarily the authority to make changes – in this way the decision making and control remains with the health care professional who maintains their monopoly of expertise and knowledge. Rather than working with the patient, some health care providers '*distance themselves from their patient's actions, judging and labelling rather than analysing and understanding*' (Trostle, 1988 p. 1305).

The terms '*adherence*' and '*concordance*' have been suggested as alternatives to '*compliance*', the latter suggesting more autonomy in defining and following medical treatments (Lutfey and Wishner, 1999). There is an implication that social and personal, rather than solely medical, factors are of importance. Some see this as more appropriate to diabetes care as patients actively manage and define their own condition (Davies et al., 2008; Lloyd et al., 2008, Lloyd and Skinner, 2009). However, advocates of empowerment and self-management argue that there is no place in diabetes care for the concepts of

compliance and adherence (Glasgow and Anderson, 1999). The compliance approach defines patient behaviour in terms of professional expectations, and rejects behaviour that contradicts this view. An alternative is the empowerment model where goals for care will reflect the expectations of the person with diabetes in a positive non-judgmental way (Anderson, 1995b; Anderson and Funnell, 2010). The resulting behaviour itself may be the same, but the underlying philosophies will differ. Either way the person will be exercising their power to behave in a certain way, but as a result of, rather than in spite of, the relationship between the professional and the person with diabetes.

2.3 Empowerment

This section develops the concept of empowerment as there is a need for consideration of empowerment as a growing trend in diabetes care (Anderson, 1995b; Anderson and Funnell, 2010). It is relevant to this study because all women with insulin treated diabetes are in relationships with health care professionals who may be perceived in hierarchical terms as being in positions of power. An empowerment approach allows for a more equal distribution of power within interactions with health care professionals, with the person with diabetes playing a more active role. Empowerment underpins current diabetes policy (DOH, 2001, 2004, 2005, 2010; Lloyd et al., 2008) and may influence how women with diabetes manage their lives in this context, by allowing for greater partnership in decision making in relation to their care. One of the key recommendations in the review of services for diabetes undertaken in 2000 (Audit Commission, 2000) specifically refers to patient empowerment, and patient-centred care is identified as a priority within the Diabetes National Service Framework for England and Wales (DOH, 2001). In contrast to more traditional approaches to care, the NSF for diabetes (DOH, 2001) has embraced the concept of empowerment. Standard Three of the NSF for diabetes specifically refers to empowerment and states:

All children, young people and adults with diabetes will receive a service which encourages partnership in decision making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate form and language. Where appropriate parents and carers should be fully engaged in this process.

(DOH, 2001, p. 5)

Empowerment may be conceptualised as a dynamic process of becoming, rather than a static process. Kieffer (1984) identifies 4 stages to this process:

- 1 **Era of entry** – this consists of demystifying authority and power structures. The amount of participation is unknown – this could apply to an initial meeting between someone who has diabetes and a health care professional where the boundaries of power have not yet been demarcated.
- 2 **Era of advancement** – opportunities occur for collaboration and problem-solving in a mutually supportive relationship – this may apply to the development of a relationship between the practitioner and patient, and exploring issues related to living with diabetes.
- 3 **Era of incorporation** – this involves confronting barriers to self-determination. These may be events that are related to diabetes in a medical or a social context such as undertaking training to enable adjustment of insulin in relation to appropriate eating. An example of this is the Dose Adjustment for Normal Eating (DAFNE) programme (Lawton and Rankin, 2010).
- 4 **Era of commitment** – this final stage concerns the integration of new knowledge and skills into everyday life, and is likely to be self-care practices in relation to diabetes or interpersonal skills that enable management of the diabetes in a way that is acceptable to the individual.

Empowerment may be viewed as an abstract concept, generally perceived as being positive and proactive. Power and the exercise of that power merge in empowerment as a

social and political phenomenon. Empowerment has been associated with attempts to increase the power and influence of oppressed groups in terms of social action since the 1960's, including the feminist movement representing the rights of women, and with self-help movements since the 1970's (Skelton, 1994). However, it is a complex concept, with personal and collective connotations and may occur at an individual, social and political level. At an individual level, Gibson (1991) described it as a '*complex and multidimensional concept ... a process of helping people to assert control over the factors which affect their lives*' (p. 354). It can be seen in a social context as '*a social process of recognising, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilise the necessary resources in order to feel in control of their own lives*' (p. 359). Rappaport (1984) has argued that it is a diffuse and socially constructed entity, individually experienced either as perceived or actual, process or outcome. He defined it as '*a process: the mechanism by which people, organisations and communities gain mastery over their lives*' (Rappaport, 1984, p. 3). As a social construction it is defined by the individual concerned, and involves relationships with others, and cannot be standardised within a single definition. At a socio-political level Katz (1984) described a political model of empowerment drawing upon synergy i.e. if people or communities work together, the result of their combined efforts will be greater than that which would have been obtained solely from the sum of their individual efforts. In the context of this study, this could refer to a combination of the knowledge of women with diabetes and that of the health care professionals.

It is perhaps in the context of relationships between people with long term conditions and health care professionals that the reality and rhetoric of the concept of empowerment can be found. Lorber (1997, p. 40) describes the differing perspectives of the '*voice of medicine*' and the '*voice of the lifeworld*'. There is a need for both voices to be heard to understand an illness in its entirety, although there is an acknowledgement that the voice of medicine usually prevails. Ainsworth-Vaughn (1998, p. 176) describes an

important personal resource for people as *'the ability to make sense of illness and to let others know how they construe what has happened'*.

Traditional relationships in medical encounters have been viewed as taking place between the dominant experts (the health care professional), and the passive patient. Ainsworth-Vaughn (1998, p. 6) described medical encounters as traditionally being *'asymmetrical interviews'* with doctors asking the questions and patients answering them. Empowering relationships require mutual respect and trust in an equal relationship, with positive interactions and mutual trust and reciprocal understanding of health care needs (Nyatanga and Dann, 2002). Paterson's (2001) study of self-care decisions of people with diabetes concurred with the view that collaborative partnerships were necessary for people to actively participate in decisions regarding their diabetes management. If this did not occur, one strategy was to lie about their self-management strategies. However, Opie's (1998) study of empowerment in health care highlighted the contradictory nature of elements of the concept, in that although the language of empowerment was used, the behaviour of health care professionals demonstrated an ingrained adherence to principles of a paternalistic relationship and the patient undertaking a 'sick role' (Parsons, 1975). Opie concluded that language and behaviour need to be consistent for empowerment to occur. Tuckett et al. (1985) put forward the argument that in fact medical consultations are meetings between experts, as the patient is as well informed and competent at dealing with their own life as the physician is clinically competent. One of the issues with this view is that although self – determination is a desired outcome of an empowering relationship, it may not necessarily be healthy if viewed in purely medical terms, as true empowerment leads to an individual having the ability to make choices and to take responsibility for those choices, taking into account the degree of risk involved (Aujolat et al., 2007). Recognition of the uniqueness of each individual is inherent in an empowerment model, allowing them the freedom to choose between behavioural options. Bradbury-Jones et al. (2008) noted that self-determination resulted in self-management, but reporting to health care professionals for treatment and advice is still required for

patients to obtain their medication. Working within an empowerment model should eliminate the concept of success or failure, but blood glucose levels are expected to fall within certain parameters for blood glucose control to be deemed satisfactory and health care policy and practice remains largely determined by health care professionals at local and government level, meaning that a biomedical approach continues to predominate.

Consultations between health care professionals and patients provide opportunities for an empowerment approach to be implemented, and Szasz and Hollender (1956) described a typology of relationships between doctors and patients including the following:

- a) ***Activity–Passivity*** – this involves an active physician and a passive patient. It could be likened to a relationship between a parent and an infant. Applications of this model in diabetes care could be in a life-threatening situation such as diabetic ketoacidosis or in the treatment of severe complications of diabetes.
- b) ***Guidance–Cooperation*** – this applies to acute disorders, where the patient is able to respond and take an active role in their care, but would be expected to follow advice given. An example would be advice to follow if an infection is present. If such orders are not followed, the patient may become labelled as being '*non-compliant*'. This may be likened to the relationship between a parent and an older child or adolescent.
- c) ***Mutual Participation*** – this may be useful for management of long term conditions where the person with the condition carries out the bulk of the treatment themselves and sees a health care professional only occasionally. The nature of the relationship is such that the professional helps the patient to help themselves and listens to their point of view. Because the experience of living with diabetes is a socially constructed phenomenon, it will differ between individuals depending upon their social context. Individuals organise and shape the nature of

their own disorder to some extent and a degree of negotiation may be required with the health care professional(s) involved in their care.

The bulk of diabetes care in the community would fall into this last category and most closely resembles an empowerment approach to care. This is likened to a relationship between two adults. Specialised knowledge is not usually available to those who have not undergone professional education, although this has changed with the advent of the Internet and Expert Patient programmes (DOH, 2004). It could equally be said that experiential knowledge is unavailable to those who have not lived with diabetes; therefore a degree of mutual participation is necessary. Mutual participation implies a partnership, and Silverman (1987) argues that this is preferable to autonomy although that may be both emancipating and constraining. In order for true mutual participation to occur in interactions it is necessary to recognize the contributions of both parties.

2.3.1 Empowerment and diabetes

In addition to the general literature, there is diabetes specific literature relating to empowerment. Peyrot et al. (1987) assert that in order for empowerment to occur, knowledge regarding management of diabetes is necessary, and they describe two separate domains of knowledge in relation to diabetes:

- a) **Personal** – personal experience of illness (which is often not perceived as real and legitimate).
- b) **Public** – formalised knowledge, known to lay persons and to medical practitioners (which is more impersonal and generalisable).

Today, people with diabetes are likely to have a degree of both types of knowledge, whereas the professional may only have the public knowledge – unless they have diabetes themselves. Rubin (1998) acknowledges that patients are experts in their own lives and physicians are experts in clinical aspects of diabetes, however not all practitioners and people with diabetes share his views.

Much of the work relating to empowerment and diabetes has been undertaken by Anderson, Funnell and associates at the University of Michigan since the early 1990's. In 1991 Anderson et al. (1991) developed a 4-step patient empowerment model. The following principles have been applied to patient education programmes such as Dose Adjustment for Normal Eating (DAFNE) and Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) in the UK (Davies et al., 2008; Lawton and Rankin, 2010):

- 1 Helping the patient to identify problematic diabetes-related issues
- 2 Helping the patient to identify thoughts and feelings associated with this problem
- 3 Helping the patient to identify health-related attitudes and beliefs underlying the problem and establish diabetes self-care goals
- 4 Helping the patient to develop and commit to a plan for achieving the goal.

Rubin (1998) also acknowledged that there is a need for a move away from traditional teaching methods, towards education and counselling approaches, and a willingness to accept that the person may not wish to change their behaviour. The role of the professional is to make sure that they have heard all aspects of the experience of illness, not just the physical. It is important that there is understanding of the medical aspects of diabetes. In an empowerment model, if a decision is made by the person affected for which they are willing to take responsibility and are aware of the potential risks, which is at variance with the optimum medical outcomes, they should still receive support, even if the professional does not agree with their actions.

There have been a number of studies concerned with the implementation of the empowerment approach to diabetes care. In a randomised controlled trial, Anderson et al. (1995a) found that participation in a patient empowerment programme resulted in improved psychological self-efficacy and more positive attitudes towards diabetes. Blood glucose levels also improved. The researchers acknowledged that their self-selected sample consisted mainly of assertive and educated people who may have been more

willing to engage with the principles of the programme. The philosophical assumptions underpinning the study were *'that patients given the freedom to choose and the opportunity to reflect on their lives would be willing and able to select appropriate goals related to living with diabetes'* (p. 947), and also that *'the empowerment philosophy is based on the assumption that to be healthy, people need to have psychosocial skills to bring about change in their personal behaviour, their social situations and the institutions that influence their lives'* (p. 944). This firmly sets empowerment within a social context.

In his comparison of the medical model and the empowerment model Robert Anderson (Anderson, 1995b, p. 413) defines the philosophy of the patient empowerment approach in diabetes as *'an approach that recognises the unique role and responsibilities of the patient in the daily treatment of diabetes'*. This differs from the traditional medical model where the physician makes decisions and is *'in charge'* of the patient, particularly within an acute care setting. They are viewed as active, powerful and knowledgeable, in contrast to the patient (the activity – passivity model described by Szasz and Hollender (1956), discussed in Section 2.3). The empowerment relationship requires an adult to adult approach – similar to the mutual participation relationship described by Szasz and Hollender. Anderson states that trying to fit current diabetes care into the medical model does not work and only leads to frustration on both sides when an attempt is made to do so. This may mean that the person with diabetes is left in limbo and may be put into the position of making uninformed, and sometimes dangerous, decisions which may be viewed by some health care professionals as being *'non-compliant'*.

Feste and Anderson (1995) describe fundamental differences between the compliance and empowerment approaches. Empowerment assumes that the individual is able to make choices and to be responsible for those choices. They are able to define and achieve their own goals within their social context. Compliance reduces patient autonomy and constrains freedom of choice, whereas empowerment increases autonomy and freedom of choice. Empowerment education focuses on daily living, whereas compliance focuses on behaviour leading to desired medical outcomes. Feste and Anderson describe

four pillars of empowerment as '*awareness, freedom, choice and responsibility*' (p. 142), resulting in the ability to take informed choices about their own care and to take action over their own lives. A major value underlying the philosophy of empowerment in diabetes care is to provide care that meets the needs and expectations of the individual. This may mean that they choose to remain dependent or to become independent, but they are enabled to make an informed choice. More recently, Anderson et al. (2000) developed and assessed a new scale to measure empowerment; the Diabetes Empowerment Scale, in the US. They concluded that their preliminary results suggested that the new scale could help to understand psychosocial adjustment to diabetes.

Skinner and Cradock are proponents of the empowerment approach to diabetes care in the UK (Skinner and Cradock, 2000). They adopt a similar approach to Anderson in that they define empowerment as involving five key features – acceptance, affect, autonomy, alliance and active participation (Skinner and Cradock, 2000). They suggest that physical and mental health will be enhanced if such a model is adopted. Research in the field of empowerment in diabetes care is beginning to emerge, and Skinner and Cradock's limited literature review (Skinner and Cradock, 2000) suggests that there is a theoretical rationale and increasing descriptive data to support this. However, research that fully tests the empowerment model is awaited. In their response to comments on their initial paper (Skinner and Cradock, 2001) and referring to the work of Robert Anderson, they ask that professionals '*remember that individuals with diabetes make 99% of the clinically relevant decisions about the treatment of their diabetes on a daily basis, that individuals with diabetes take responsibility on a daily basis for the outcome of these decisions, and as such our role as health care professionals is to endeavour to ensure that these are informed not ignorant decisions*' (p. 26).

In conclusion, three areas of literature relating to women and diabetes, stress, and empowerment have been used to address the focus of this research which concerns the experiences of middle aged women with insulin treated diabetes who lead busy lives. The review of the literature indicates that a type of knowledge that complements existing

biomedical knowledge about diabetes is required to reflect the complexity of living with diabetes, as indicated below. Although the biomedical model of care continues to predominate there is a growing body of knowledge and opinion that psychosocial factors are central to women's health.

The social construction of gender implies that women's health can be understood only by a better appreciation of psychological aspects of women's lives, along with more integrative biological research. Indeed, every health discipline, with the notable exception of medicine, recognises that psychology and the social sciences must be central to, and at the very core of a woman-centred and women's health movement.

(Hamilton, 1993, p. 51)

In recent years there has been a gradual move towards psychosocial and empowerment models in clinical practice for diabetes, reflected in more holistic approaches and provision of care by multidisciplinary team members, although the proportion of qualitative psychosocial research remains small in relation to quantitative biomedical studies. It is my contention that more qualitative research is needed to support and inform clinical practice. Another observation made as a result of both clinical experience in diabetes care and a review of literature is that much is written from the perspective of health professionals, rather than from that of the women with diabetes themselves, an observation also made by Koch et al. (2000).

The present study differs from and adds to previous research by focussing solely on women with insulin treated diabetes, and within a specific age range. Only women whose diabetes is treated with insulin have been included, and all women are resident within the United Kingdom. It does not aim to test hypotheses, but to add to existing knowledge about the nature of stress in relation to diabetes, and the impact upon women's lives, which can be applied to clinical practice, within a qualitative research framework.

Following the literature review the following research questions have been developed:

- What do women describe as stressful in relation to their insulin treated diabetes?
- What impact do these stressors have on women's lives?
- How do women with insulin treated diabetes interpret and manage their lives?

The following methodology chapter discusses how best to answer these questions, leading to a qualitative research design. The concept of empowerment is continued within the next chapter as it has been used to implement a methodology where women were encouraged to be creative in their data reporting methods. The aims included making women's voices heard, an empowering process in itself and which reflected the aims of the NSF for diabetes (DOH, 2001).

CHAPTER 3

Methodological theory and praxis

This chapter is concerned with both the paradigmatic and theoretical methodological underpinnings of the research study, and the ensuing research methods employed to answer the research questions posed. Ethical issues will also be examined. Before examining the methods used for data collection, the ontological and epistemological basis for the study will be addressed – the understanding of ‘ways of knowing’.¹

As a researcher and woman, my methodological choices were influenced by an underpinning feminist ideology which guided the research process, and it is feminist theory that I first consider below.

3.1 Theoretical framework – feminist theory

Macpherson (1983, p. 345) asserted that feminist theories formed part of a new paradigm for nursing research, in that they joined with existing biopsychosocial and holistic theories. After conducting my review of the literature it would seem that many feminist theories and postmodern feminists (Lather, 1991; Weedon, 1987) contend that there is no one grand feminist theory, which in itself has the potential to become hegemonic, but rather different theories derived from different roots. Similarly, Reinharz (1992, p. 6) argues that a pluralistic approach to feminism exists depending upon the context and the theoretical base. A range of feminist perspectives are given below.

¹ Epistemology refers to the theory of method or the grounds of knowledge, and ontology to the branch of metaphysics dealing with the nature of being.

Stanley and Wise (1993, pp. 61–64) describe three central themes of feminism:

- a) Women are oppressed, which has consequences for everyone else in society.
- b) '*The personal is the political*'. This may be interpreted as the notion that power can be examined within personal life and therefore the '*system*' (the political) cannot be separated from personal experience within a social structure (p. 63).
- c) The existence of a feminist consciousness, which they describe as '*seeing the same reality differently*' (p. 64). This concept has similarities with feminist standpoint theory (Hartsock, 1987; Smith, 1987), which suggests that women have a unique viewpoint, which differs from the dominant patriarchal viewpoint, or epistemological privilege from which to approach research, by virtue of their oppressed position within society and that assumptions underpinning traditional research paradigms are gendered in favour of men. Stanley and Wise suggest that there are many differing and diverse standpoints among women rather than one standpoint, which would have a positivist connotation of being the only one (Stanley and Wise, 1983).

A feminist approach to research would entail adopting a '*conscious partiality*' (Mies, 1993, p. 68) where the researcher adopts a partial identification with the research participants. Female researchers become '*outsiders within*' (Harding, 1991, p. 131) when they and the participants are both female. Understanding women's lives from a feminist exploration of experiences produces a more complete knowledge than that produced by men only, the subjugated position of the researcher providing the possibility of a more complete understanding. The decision to study women only in this thesis was a conscious one.

3.1.1 Feminist theory and critical social theory

Feminist theory may be seen as closely allied to critical social theory, in that it seeks to understand and to contribute to change, specifically, the oppressed position of women. Critical social theory is concerned with improving situations, especially where there are

institutional sources of resistance to change where hegemonic practices exist. In terms of this research, hegemonic practice is defined as the medical treatment of diabetes, a definition imposed by and based upon a biomedical model. Crotty (1998) describes critical theory as emphasising that culturally constructed meanings exist to serve such hegemonic interests and support power structures, in this case medical meanings attached to diabetes. These meanings therefore work in opposition to equity and contribute toward oppression. Diabetes is a disease that affects the whole person, not just the pancreas which produces insulin. It is therefore inappropriate to apply a model which responds to physiological symptoms rather than the whole person. Critical theory is also relevant to this research, as it is concerned not just with a desire to understand information, but also aims to improve social outcomes, which may meet resistance from those who have a vested desire to maintain the status quo.

The use of critical social theory in research starts with the assumption that people are capable of self-reflection. It starts from the premise that some groups are in a subordinated system within an institution or social context, in this case the participants being women and patients within a health care system. To some extent, using this paradigm, I am also in a subordinate position, being a woman, having a student status and a nurse in a hierarchical professional structure. In terms of the research process however, there is an in-built difference in that I am in a more powerful position than the women involved as I initially decided upon the research topic and the research process in terms of the methodology and the ensuing methods of data collection. The balance of power may change as the research progresses, as initially the participant has the power to decide whether to take part in the study and what information to share, with the power passing to the researcher as the data is taken away to analyse and interpret. Traditionally, research participants are more powerless than the researchers and less likely to have the opportunity to comment (Roberts, 1992), although researchers are dependent upon the goodwill, participation and time of the respondents. Both parties have needs which require addressing and agendas identified within as near a non-

hierarchical framework as possible. I have tried to create an atmosphere of more active and equal participation to some extent by asking for volunteers, not asking for medical permission for women to take part in the study and to base the data collection tools on issues identified by some of the women themselves as well as on my own experience and literature based evidence. Egalitarian ways of disseminating the research findings will include sending reports to participants for comment, incorporating any such comments and recommendations into the final document and publishing in arenas that are accessible to a wide audience, both lay and professional.

It could be argued that research about women carried out by nurses is an example of one oppressed group carrying out research with another, which makes the research more egalitarian. Although nurses may be seen as part of the existing power structure, Chavasse (1992) argues that they are an oppressed group and are in need of empowerment themselves. Nurses have been described as oppressed by Gibson (1991) because of their unequal power relations with medical staff and by Lovell (1982) as an oppressed group because of their gender. Gender is described as a social construction by Lorber (1997, p. 5) and impacts on illness through economic circumstances, work and family responsibilities, lifestyle choices, social interaction with family members and other intimates and interactions with health care professionals- areas which this thesis will explore. Traditional areas for research in diabetes and women's health – menarche, pregnancy, menstruation – are largely approached from a biomedical point of view utilising physiological measures of hormones as discussed in Section 2.1.1. The physiological measure of male or female provides the focus, a purely physiological measure. Gendered psychosocial aspects of diabetes such as eating disorders are often measured in quantifiable terms as discussed in Section 2.1.3, rather than to ask participants for their narratives of experience. This research aims to redress this imbalance, but does not automatically assume that such aspects of diabetes are stressful or major experiences, and are only addressed if they are raised by the women themselves.

3.1.2 Feminist theory and empowerment

These concepts are considered together as they are closely allied, particularly in relation to power. This research does not claim to be true participatory research where there is sharing of control throughout the research process, however, the principles of empowerment are embedded within it.

Empowerment is embedded in feminist research in that it adopts the viewpoint of seeking improvement for women in particular, in social, political and/or economic terms (2007). Examples of how it may be used may be in adopting a critical social theory approach (Bondi and Buman, 2001), participatory action research (Gatenby, 2000) or as in the case of this study, an interpretative phenomenological phase of a mixed methods approach. Whichever approach is adopted, the principles of empowerment remain the same, it is in the application of these principles that the nature of the research is shaped. Research adopting a critical social theory perspective may be concerned with influencing change within the political agenda, whereas an interpretative phenomenological approach is concerned with illuminating the issues that affect women's lives, in this case those in both the psychosocial and medical contexts of living with diabetes, thereby exposing their stories which are multidimensional and complex. As well as feminist researchers adopting a feminist epistemology which will in turn affect the methodology and methods of the research process, they are also concerned with the issues of power within the research process, and aim to seek methods that empower the participants as well as the research and the researcher (Leckenby and Hesse-Biber, 2007). In my research, a sense of openness, consideration and trust was engendered during the interviews and the content of the journals I asked the participants to complete was decided upon by the research participants themselves with no influence from me. Although this study makes no claims to adopt a participatory research approach, participants were encouraged to contribute their views as to the relevance of the topic during the focus group, comment on drafts of the survey design and interview schedule, and were sent a preliminary narrative of the

analysis of interviews for comment (see Sections 3.4 and 3.5). The research process was therefore concerned with researching *with* and not *on* women (Scanlon, 1993).

There is no single definition of empowerment and that offered by Mason et al. (1991) has been adopted for this study as a '*mutual process of sharing and development*', involving a sharing of resources from the researcher and the research participant. The aim of a feminist approach to this research is to enable the research participant to '*find one's voice*', that is for the researcher to gain an understanding of a phenomenon and find a way of communicating it. Opie (1992, p. 64) suggests that there are three ways of research participants becoming empowered. These are by a) contributing to making an issue visible where it may have been previously hidden; b) having a therapeutic effect by reflecting and re-evaluating experience and constructing a version of reality with the researcher; and c) there may be a subversive outcome as a result of questioning or challenging the dominant discourse. This research addresses all of these issues by making women's knowledge more visible and challenging the hegemonic discourse of medicine. I believe that the research may have had a therapeutic effect for those women taking part, but there was also the possibility of an adverse effect, as reflections may not necessarily have been upon positive experiences and consciousness may have been raised, which would have ethical implications.

A pluralistic mixed methods approach is in keeping with these underlying feminist principles (Creswell et al., 2006; Deem, 2002; Shapiro et al., 2003), particularly when viewed from a Transformative–Emancipatory perspective (Mertens 2003) in which the centrality of male power in the social construction of knowledge is exposed (the medical discourse in this thesis), which reflects the power and social relationships within society. The aim of such research is to enable improvement in diabetes care as a result of the inclusion of knowledge derived from alternative sources of knowledge from groups other than the dominant one. An inclusive and emancipatory approach to research is adopted, congruent with the principles of feminism and empowerment. Translating these principles into practice for my own research has involved defining an area for research based on the

experience of women themselves and from clinical experience. The thesis looks to make a contribution to the improvement of the lives of women with diabetes, although those taking part in the research may not experience an effect themselves. Dissemination of my research findings can be seen as an important aspect of a feminist approach to research, in that it is expected that the results will be used for positive change. My role as researcher becomes that of a mediator and an advocate for the women with diabetes. The researcher's perspective will be influenced by a variety of experience, in this case my professional experience in a largely biomedical framework, reflexivity from being a part of the research process, and data offered by the women about their experiences. Empowerment through dissemination will mean that publications will need to be written in a style and language that is accessible to all, so that the meaning is clear to all participants in and recipients of the research, whether they are lay, academic or professional, meaning that different sources for publication and modes of dissemination may need to be accessed for different audiences (see Chapter 9). Anderson suggests that if the research is manipulated to conform to scientific principles and is not used to improve women's lives, then it becomes an oppressive practice in itself (1991, p. 118). Sherwin (1992) draws attention to the fact that those with the most need to be empowered are those who are most likely to be excluded from the discourse (a principle which could also arguably be applied to the research process) – *'those with the power to set the social agenda and define the realms of knowledge view the world from their own perspective. Hence in the realm of health care, the professionals who make the decisions about policies and priorities are most attuned to the needs that arise among the types of people that they know best – other people with power and privilege within society'* (p. 232). She therefore draws attention to the need for a transition from hierarchical structures to a more egalitarian, equitable power distribution between patients and practitioners (or researchers and participants) and for the recognition of voices that have been previously unheard. Narrowing the gap between lay and expert knowledge, and learning from each other, is part of the process of empowerment described by Funnell

and Anderson (1991) and is central to the aims of this research. The following section discusses the theory underpinning the methods used for data collection in terms of a feminist empowerment approach.

3.1.3 Feminist methodology

Harding (1987, p. 3) describes methodology as a '*theory and analysis of how research does or should proceed*', in contrast to method which she describes as '*a technique for (or a way of proceeding in) gathering evidence*' (p. 2). (A separate section on method follows – Section 3.4.) The methodology for this research is based upon the theoretical frameworks described above, with the aim of creating a space for women to tell their stories. The methodology is characterised by the position from which the research questions are asked, and the political and ethical issues raised (Maynard, 1994).

As previously argued, there is no one single definition of feminist methodology, but the research occurs in a framework of gender divisions, oppression or patriarchal control, and informs our understanding of the social world. I have interpreted patriarchal control as the scientific basis of medicine which dominates much decision making in the field of diabetes care. I have taken feminist methodology to mean research by a woman with other women, which values subjectivity and personal experience, based upon Duffy's (1985) criteria, which I believe this research to fulfil, as set out below.

Duffy (1985, p. 345) identifies 8 criteria for feminist research:

- 1 Principal investigator is a woman.
- 2 Feminist methodology is used (defined as a research approach characterised by one or more of the following: interaction between the researcher and the subject; non-hierarchical relationship between the researcher and the subject; expression of feelings and concern for values.)
- 3 The study has the potential to help the subjects, as well as the researchers.
- 4 The research is focused on the experience of the woman.

- 5 The purpose of the research is to study women.
- 6 The word feminist or feminism is used in the report.
- 7 Bibliographic references to feminist literature are included.
- 8 Non-sexist language is used.

Crotty (1998) questions the existence of distinctive feminist methodologies or whether such methodologies provide a feminist perspective on existing methodologies, the latter being a view to which I subscribe, that is that there is no one way to do feminist research. Maynard and Purvis (1994) regard a focus on women's experiences, concern for ethical questions and the role of the researcher as important aspects of feminist research, all of which are addressed in this thesis. In keeping with the postmodern approach which suggests that there is no one correct feminist methodology, Fonow (1991, p. 5) states that '*carefully designed research grounded in feminist theory and ethics is more useful to understanding women's experiences than an allegiance to any one particular method as more "feminist" than any other*'. Attention to the affective aspects of the research is seen as being part of the critical reflexivity which characterises a feminist approach to research.

The term 'critical reflexivity' has been used to refer to ensuring the rigour of qualitative research and incorporating the use of a researcher's reflexive journal as a data source (Bradbury-Jones, 2007). However, in the context of this study, the notion of critical reflexivity refers not to rigour, but to the acknowledgement of the nature and function of power within the research process (McCabe and Holmes, 2009), which can be used to achieve the goals of empowerment and emancipation central to feminist research. In this study, empowerment can be interpreted as enabling women with diabetes to be actively involved in defining the world within which they live, rather than accepting an imposed medical definition. Although production of a co constructed narrative is an outcome of the research, it is the researcher's standpoint, social position and interpretation of the data provided by the participant that influences the production of this co construction, rather than actual data provided by the researcher. For this reason, data

collected in my reflexive journal was not included in the thesis. The participant is seen as the expert and the researcher purely as a facilitator of the production of previously subjugated knowledge. Critical reflexivity therefore may be used as an empowering tool, leading to new insights and the acquisition of new knowledge.

This is a view consistent with that of Gubrium and Holstein (1997, pp. 57–74) in terms of their depiction of the notion of '*emotionalism*', which is not necessarily a gendered perspective in itself. Emotion is seen as an integral part of lived experience and of the research. The experience of thoughts and feelings are part of the research for both the researcher and the participant. It is important to note that there is a difference between becoming emotionally involved with the participants and acknowledging feelings in the context of the research. The former could foster feelings of dependency, which would be against the principles underpinning this research. Emotions can be accessed through what Gubrium and Holstein call '*various surfaces of experience*' (p. 62), such as talk, gestures, posture. This may involve the experience of emotions and feelings in response to what is being told, or demonstrated. Emotionalism is a powerful concept in that it may result in change for both parties, as it is a two way process.

In terms of feminist methodology I come to this research as a white, middle class woman in midlife; a mature student with roles as a wife, mother and carer; and experience as a nurse working in the practice and education of diabetes care mainly within a positivist medical model. I also have a sense of the limitations of such a model. I therefore have an active role in shaping the research process, and would do so regardless of my background, but may approach it from a different viewpoint. If the research were primarily positivistic in nature, this active role could be described as bias affecting the reliability and validity of the results. However, in terms of the qualitative element of the research, subjectivity and reflexivity are valued as integral and necessary parts of the research process. The following section is concerned with the development of the research methods within the feminist theoretical frameworks described.

3.2 Research paradigms

In ontological terms, research paradigms provide the basis for the development of methodology and research methods. Cryer (1996, p. 55) refers to a research paradigm as *'an overriding viewpoint that shapes ideas and actions about the conduct of research and the validity of its findings'*. This is not dissimilar to Denzin and Lincoln's assertion that a paradigm is *'a basic set of beliefs that guide action'* and is made up of ontology, epistemology, methodology and ethics (2000, p. 157), although these may not be easily separable.

This research study positions itself at what Miller and Crabtree describe as being at *'the place where the walls meet clinical reality'* (Miller and Crabtree, 2000, p. 608), providing a vehicle for the voices not usually heard. The walls are described as a place where *'very different ways or cultures of knowing can meet and converse'*, in this case the interface between the practitioner and the person with diabetes. *'Multiple paradigms'* and *'new hybrids'* (Miller and Crabtree, 2000, p. 609) are described as emerging from clinical experience, which frame the research design to provide a different kind of knowledge from that usually gained from clinical research, i.e. that of those who live with diabetes who possess a tacit knowledge rather than that of scientific knowledge.

In epistemological terms, this leads to a mixed methods approach, where a combination of quantitative and qualitative methodology attempts to identify a common ground between the biomedical and experiential worlds of those living with diabetes, which involves a shift in emphasis from the disease being the focus of the research questions, to the personal experience becoming the entity in question. Although still requiring interpretation, quantitative research adopts an objective positivist approach where there is a single truth, whereas qualitative research is concerned with subjectivity and accepts multiple versions of reality. In terms of this research, the objectivity comes in the form of the medical diagnosis and treatment of diabetes within a positivist medical model, with diabetes defined as a relative or absolute lack of insulin, and the subjectivity

is the experience of the women living with diabetes – each engages with the other.

Diabetes is a physiological condition based on a biological malformation which has a psychosocial impact on individuals. The research starts from the premise that diabetes is more than a biological malfunction based on a biomedical model, but accepts that it is mainly defined as such by professionals working within the field, and by some women with the condition, and therefore cannot be discounted. By representing women's constructions of their experience of diabetes, it is hoped that an area of shared knowledge, from both an objective (medical) and subjective (social) perspective will emerge which can be used in both clinical practice and by the women themselves and may contribute to equalising the power differential between the two. One concept identified as being central to the research, stress, could be regarded as a social construction² which exists in contemporary Western society i.e. the social and the historical context of the here and now. However, this is not to say that it cannot also be measured by quantifiable methods, as well as utilising qualitative research techniques.

A mixed methods approach is based on the notion that the research design is based on '*thoughtful choices*' (Coward, 1990, p. 163) i.e. critical thought and pragmatism, rather than being constrained by particular paradigms. The approach may incorporate both critical perspectives and procedures and the '*research question and method choice are approached from the perspective of making thoughtful choices among multiple options to study the complex phenomena of interest*' (Coward, 1990, p. 168).

This thesis aims to utilize such a perspective, addressing the complexity embedded within the research questions, which goes beyond biomedical principles, and also explores the associated psychosocial aspects. A sequential mixed methods approach was adopted which developed as the research progressed. An exploratory design is best suited for exploring a phenomenon (Creswell and Plano Clark, 2007). The results from each stage of

2 Social constructionism is concerned with common understandings, or constructs, that are created and shared by the majority of people in a society, within a particular historical and cultural context

the research connect to the subsequent one, and one type of data is collected at a time. Greater emphasis is placed on the qualitative, rather than the quantitative, stages of the research process. An integrated approach is necessary to address complex questions that arise from clinical practice and experience, rather than being forced into a specific methodology. As in the case of this research, the methodology influences the data collection methods which may arise from the process of doing the research, rather than being defined from the outset.

A mixed methods approach rejects the incompatibility thesis postulated by Howe (1988) that quantitative and qualitative methods cannot be mixed. This thesis adopts the methodological pluralism, or eclecticism position, of Burke Johnson and Onwuegbuzie (2004) and accepts the premise that there are fewer differences between positivist and interpretivist paradigms than previously supposed. Examples of similarities between quantitative and qualitative research are that so-called positivist and objective research must always involve a degree of human decision making and interpretation of data throughout the research process, whilst mathematical principles such as triangulation are employed within the subjectively described qualitative research (Symonds and Gorard, 2010). Mixed methods research recognizes the existence and importance of the natural world as well as psychological and social constructs of reality. Knowledge is therefore constructed, but also based in the reality of the world. This is relevant to this thesis as the psychosocial nature of the experience of diabetes is examined, but is embodied and related to scientific principles of blood glucose metabolism.

Because of the already existing similarities between research paradigms that have previously often been regarded as divergent, Symonds and Gorard argue against the positioning of mixed methods research as the 'third paradigm' suggested by Tashakkori and Teddlé where movement between methodologies is accepted (Tashakkori and Teddlé, 2003, p. ix). Mixed methods research draws upon the strengths of both quantitative and qualitative research and employs relevant criteria to judge the rigour of the research process (see Section 3.5.4). A pragmatic approach to the research is

adopted, which utilises relevant methodologies to answer the research questions asked, making ontological positions less meaningful, thus making research methods transferable across paradigms. As in the case of this thesis, such research is often complex and dynamic in nature, with practical application of the results being an aim of the research. In terms of dissemination of research findings, mixed methods can appeal to a wide audience and aid communication between diverse groups, in this case both professional and lay.

A strength of mixed methods research is that data collected using different methods results in '*complementary strengths and non- overlapping weaknesses*' (Burke Johnson and Onuegbuzie, 2004, p. 18). A greater diversity of views is represented and in the case of the sequential exploratory approach taken in my research there is allowance for greater expansion of understanding of a phenomenon and representation of a greater diversity of views.

In spite of the rejection of a positivist approach by second wave feminists in the 1960s and beyond (Mies, 1983; Smith, 1987; Stanley and Wise, 1983; Wheeler and Chin, 1989), feminist epistemology is congruent with that of mixed methods. Feminist theory links the concepts of male supremacy with female oppression. Quantitative research has traditionally been adopted within a positivist paradigm where there is a tendency to reduce participants to subjects and to prove a previously identified hypothesis. This may be classed as research *on*, rather than research *with* participants. Feminist research allows for the inclusion of the viewpoint of women and their social realities across a wide range of perspectives and practices. Linkage is made between epistemology, theory and method. Multiple methods allow for the inclusion of multiple voices, in keeping with this epistemology. Women are not a uniform group; therefore a range of approaches may be relevant to access their experiences. Similarly, women with diabetes do not form a '*diabetic*' group. They are women who happen to have diabetes, with individual experiences.

Feminist research has the capacity to cross epistemological boundaries and can speak from both positivist and constructivist points of view. Data collection tools can be adapted to represent the views of women. In themselves, research methods are neither feminist nor non-feminist, it is the way in which they are applied which makes them so.

Leckenby and Hesse-Biber (2007) refer to three paradigmatic approaches – purist, pragmatic and dialectical. By definition, a mixed methods study such as this cannot adopt a purist point of view to epistemology and methodology, where a particular paradigm is adhered to. In feminist terms, adhering to a single approach limits the knowledge produced and is therefore anti feminist in nature by imposing false boundaries and limits to knowledge. The pragmatic approach, to which this thesis ascribes, utilises the methods most appropriate to answer the question(s) posed. The research approach is entirely grounded in the needs of the research design, and is concerned with the outcome of the research and not with epistemological debates. The third approach is the dialectical approach which is concerned with both dissonance and harmony. Differences between philosophical paradigms are recognized as existing and are considered important. The differences are deliberately integrated for the purpose of enhancing understandings, perspectives and meanings.

A feminist pragmatic approach has guided the development of the research process throughout this study and the research methods are discussed in Section 3.4. A focus group (see Section 3.4.3) was chosen as the first stage in the process as this would allow for the development of the key issues that might be of importance to women with diabetes, to evaluate the inclusion of areas identified through the literature review and to contribute to the development of a postal questionnaire for the second survey stage of the research. I did not define the experience of the women in advance and felt that an externally defined structure was inappropriate. The research questions were based upon the literature search and my professional experience, and a topic guide was developed from these. The facilitation of the focus group was based upon feminist praxis in that it was enabling participants to voice their experience of living with diabetes and

allowing access to subjugated knowledge (Leckenby and Hesse-Biber, 2007), articulated by the women on their own terms and using their own concepts and frameworks.

The results of the focus group were then used to develop a survey (see Section 3.4.4) to ascertain whether the issues identified in relation to living with diabetes were of consequence to a larger group of women. Although feminism in the past has not been supportive of a positivist approach to research as in the case of the use of surveys, this has been largely due to the fact that the participants have often been white males and been objectified as subjects rather than research participants (Brush, 1990). However, feminist empiricists such as Griffin and Phoenix (1994) argue that survey research is of value in feminist research as long as issues such as gender, culture and social context are an integral part of the research tool. For some audiences, positivist research is still seen as the gold standard and research which excludes this element may not be taken seriously, another reason for its inclusion in this study.

The survey results indicated that a qualitative phase would be useful to examine women's experiences of stress and diabetes in greater depth and were used to identify a group of women to be interviewed and given journals in which to record their experiences of living with diabetes.

The interview stage of data collection (Section 3.4.5) was designed according to feminist principles where I as the researcher with an awareness of my own feminist standpoint was aware of issues of power and authority that might affect the interview process. Although an interview schedule was available to guide the interview process, the focus was on the narratives that the women wished to vocalize and the use of this data to contribute to the experiential knowledge of living with diabetes. The interview questions were therefore concerned with accessing an understanding of the women's experiences of living with diabetes with a view to facilitating change in the provision of diabetes care for other women. Journals were offered to the women to record their experience of living with diabetes for a three month period following the interview. Although guidelines were

provided, these were deliberately non prescriptive, to enable the women to include material that was perceived as relevant to them, and to enable them to move away from the medical model of diabetes which was embedded within their diabetes care.

In terms of the analysis of the data, feminist principles were employed (see Section 3.5) in that an iterative approach was used so that the data collected and analyzed in the early stages of the research, and guided the ongoing process of data collection and analysis, allowing for the integration of the experience of all of the women into the data analysis process. My own standpoint was acknowledged within the analysis and a narrative account of the data, written in the first person but reflecting the experience of all the women interviewed, was sent to all of the women for comment. IPA was considered to be an appropriate method of data analysis, in that there was an acknowledgement that bracketing of one's own experience as a researcher would not be possible and that there was a willingness to access the complex and multilayered interpretations of the women's experience.

The criteria for the rigour of my research does not rely upon the judgement criteria embedded in positivist research designs such as validity and reliability, but widens the perspective to that of '*crystallization*' (Richardson, 2000, p. 934) where there is an acknowledgement that there are many views of the world, rather than the three referred to in triangulation. Criteria have been adopted which are suited to the feminist approach adopted within this thesis (see section 3.5.4) which acknowledge the role and feminist aims of the researcher in shaping the outcomes of the analysis, together with the emotional and creative aspects of the research in expressing a version of reality.

Representation and dissemination of the results have been constructed to represent the views both of the women involved with the research and also those wishing to access the results. It is acknowledged that some descriptive statistical analysis has been included to appeal to all groups of people wishing to access the results, including the medical profession, as it is here that change may occur in the development of future

services for women with diabetes. A creative approach has been chosen for dissemination of some of the research findings (see Section 4.2), as this research is a creative, as well as a scientific, piece of work and allows for a wider view of the experience of women living with diabetes.

It therefore follows from the above discussion of research methodology that any method may be chosen to answer questions posed in feminist research studies. Women have multiple ways of looking at their worlds and a mixed methods research approach reflects that standpoint. The aim in feminist research is to avoid privileging one view over another and mixed methods provides ways of accessing data to produce different types of knowledge according to the research questions asked.

The use of multiple methods reflects the multifaceted identity of many feminist researchers. We are multifaceted because we are working during a feminist renaissance that transcends disciplinary boundaries and challenges many of our capacities at once. Our multifacetedness makes single – method research seem flat and inadequate to explore and express the complexities of women's lives.

(Reinharz, 1992, p. 202)

A mixed methodology therefore increases choice and is therefore less repressive than a single approach, which in itself empowers feminist research. The researcher is enabled to address complex issues which occur at both the individual and societal/cultural level, allowing for the development of work that may be both creative and emotional, as in the case of this thesis where the results are represented in poetic form, a powerful way of disseminating results.

Traditionally, a desirable outcome in diabetes care has been defined by the hegemonic medical discourse with its reliance on scientific 'truth', as the attainment of near normal long-term blood glucose levels. In terms of measurable medical consequences, it cannot be argued that this is unimportant; however there may be less desirable consequences in terms of day to day living. However, there is beginning to be

an acceptance by some health care professionals (Anderson, 1995b; Baksi and Cradock, 2001; Patel, 1993; Skinner and Cradock, 2000; Walker, 1998) that scientific knowledge is only part of a larger picture in which a person-centred empowerment model (Feste, 1992; Gibson, 1991; Rappaport, 1984; Skelton, 1994) has a role to play. This is a model which this research attempts to mirror, in terms of exploration, understanding, self-reflection and finding a common ground (Miller and Crabtree, 2000, p. 617). Gathering and quantifying evidence about blood glucose levels is quick and easy, and painless for the researcher, whereas researching someone's lived experience can be time consuming, emotionally engaging for the researcher as well as for the participant and complicated to analyse. A plethora of research evidence about diabetes relates to biomedical issues, much of it using standardised measures and scales. A central tenet of this thesis is that the experiences of people with diabetes are not standardised, and therefore an alternative approach is necessary.

This research employs both quantitative and qualitative methods, the quantitative aspects being used to identify the sample for the qualitative phase, and to illustrate demographic characteristics of the sample. The main approach is qualitative, described by Oiler Boyd (1993, pp. 69–70) as *'involving broadly stated questions about human experience and realities studied through sustained contact with persons in their natural environments, and producing rich, descriptive data that help us to understand those person's experiences. The emphasis is on achieving understanding that will, in turn, open up new opportunities for action and new perspectives that can change people's worlds'*. This definition and the ethos of the research study are concomitant in terms of both process and outcome. There is likely to be an overlap between quantitative and qualitative methods as to some extent they are socially constructed and cannot therefore be value free, and are therefore not necessarily divergent approaches (Bryman, 1988). By using a combination of methods that complement each other, this research is acknowledging what is of value in the biomedical model and also highlights what is missing. I see the interaction between methods as mirroring clinical practice where

decisions are made on the basis of different kinds of evidence such as blood glucose measurements, and the taking of an individual history to produce a broad picture. Each method is of value and has its own strengths, while being different from the other. Oakley (1993, p. 214) asserts that the quantitative/qualitative divide is not as easily separable as it may first appear, and that quantitative research is still subject to the perception and position of the researcher. Their stance will shape what is written and personal values are not left behind.

Anderson (2001, p. 806) states the importance of representing experience within diabetes care by saying '*as long as diabetes remains a self-managed disease, representing the patient's lived experience faithfully will play a central role in helping us understand how to help our patients. Their stories provide us with the data necessary to develop effective educational, behaviour change, and coping strategies*'. In this research it was anticipated that much data would exist in the form of such stories. Specific events would be recounted in relation to stressful events and the women's lives. The narratives of others could also be recounted. Telling the story and what is heard by the listener constructs the story, by adding in meanings and their significance. Charmaz (2001, p. 371) describes these narratives as having a distancing effect and allows for the re evaluation of past experience by recounting it in the present, and planning for the future '*a way of creating continuity and wholeness in the face of disruption*' (Charmaz, 2001, p. 373). Such a use of narrative has been well documented by academics (Bury, 2001; Frank, 1995; Greenhalgh and Hurwitz, 1998; Kleinman, 1988) and also by women with diabetes, in the form of pathographies (Dominic, 1999; Roney, 1999; Waterston, 1995) and even as the subject of fiction (Jerkins, 2001).

It is important to distinguish between the treatment of these stories as part of a constructivist approach to research, and that adopted as a research approach by discourse analysts (Josselson and Lieblich, 1999; Kohler Reissman, 1993). Brody (1998, p. xiii) refers to a narrative as '*the bridge between teller and listener*' and expresses the view that medicine has ignored the lived experience side of the bridge. I see the

outcomes of this research as an example of two directional travel across the bridge rather than as a one way system, with knowledge being carried from both sides and shared, and also as having a bridge building function by connecting narratives of health care practice with that of women with diabetes and creating a common ground.

3.3 Ethics

Beauchamp and Childress (1994) defined four moral principles underpinning the principle-based approach to ethics. These are beneficence, non-maleficence, justice/fairness and autonomy. Empowerment is described as a combination of beneficence and a respect for autonomy and I have paid particular attention to these in designing and conducting this research. The human rights approach adopts similar principles and defines them as privacy and dignity, anonymity and confidentiality, fair treatment, protection from discomfort or harm and the right to self-determination i.e. to have freedom to choose in the absence of external controls and to make autonomous decisions.

Prior to undertaking data collection, ethical consideration was given to the proposed research. The research proposal was approved by an advisory ethics committee within the then School (now Faculty) of Health and Social Care at the Open University. At that time (2000) there was no formal ethics committee, and the ethical issues arising from this research were part of the process of the establishment of such a committee.

An important aspect of this research relates to the ethical considerations, as I am concerned that no one should be harmed as a result of taking part in the research, but also to respect the freedom of each individual to make an informed decision about whether to take part, and not be constrained by powerful others. Although the research is concerned with women with a specific medical condition, who could be construed as patients if the research were following a biomedical model, the focus is on an empowerment model, which encourages autonomy-they are women first, capable of independent thought and action. Because the women suffered from a defined medical

condition and would all be receiving a degree of professional health care, otherwise they would be unable to obtain their essential medication, I had to make a decision whether to ask for ethical clearance from NHS ethical committees, now National Research Ethics Service (NRES). However, the women with diabetes in the purposive sample were not recruited via a medical route; therefore NHS ethical clearance was not required. Advice was taken from a member of an MREC, and it was not deemed necessary to gain ethical clearance, as the research did not involve use of any NHS premises or staff, any medical materials such as medical records or results, and participants were not recruited by any NHS channels.³

However, I believe this study to be highly ethical in its approach and to adhere to the morals underpinning both the principle-based and the human rights approach, as illustrated below. Autonomy and beneficence relate specifically to the empowerment approach, but a description is given of how the research attempted to address each moral issue.

Autonomy/self-determination Recruitment was voluntary with participants responding to an advertisement within a non medical newsletter of an adult learning institution, with the participants free to participate or withdraw at any time and have the right not to answer any questions if they so wished. They were asked for written informed consent and a confidentiality agreement was drawn up for signature by myself and the research participant.

Beneficence There is some evidence that talking about experience can be beneficial – Robson (1993) suggests that *‘people often derive considerable satisfaction*

³ Local Research Ethics Committees and MRECs have been superseded by the National Research Ethics Service since the data for this research study was collected, with the introduction of the Research Passport scheme in 2008.

from talking about what they are doing to a disinterested, but sympathetic ear. Taking part in a study can often lead to respondents reflecting on their experience in a way they find helpful'.

It is hoped that the contribution to a body of knowledge constructed through the mutual sharing of knowledge, will benefit both those with diabetes and the health professionals involved in their care.

Non-maleficence/protection from discomfort and harm A potential hazard of research may be discomfort or distress caused by discussing psychologically stressful experiences. This may lead to temporary discomfort or unusual levels of temporary discomfort as described by Reynolds (1972). All participants were given the number of the Diabetes Careline, a service provided by Diabetes UK, should issues arise that required further discussion. My own professional experience has been in working with people with diabetes as a clinical nurse specialist, and a considerable part of this role was concerned with counselling and supporting people when distressed, and I felt prepared to give support should the need arise. A therapeutic outcome as a result of taking part in the study may have been an unintended outcome for some people. Researching sensitive issues in the lives of women with diabetes had the potential to lead to the experiencing of strong emotional responses by both the women and myself.

Privacy/dignity/anonymity/confidentiality – participants were reassured that all data would be treated as confidential and anonymised, whether written or audio taped. No information was divulged to any health professional involved in their care. Personal records were stored adhering to the principles of the Data Protection Act. Permission was asked to reproduce any extracts included in publications, as this was in effect making private issues public.

Justice/fairness – all participants were given an information sheet, which truthfully outlined the purpose and content of the study, with opportunity for discussion

and questioning. Assurance could be given that treatment would not be affected as I was not involved in their care and was therefore not in a position to influence that care.

I was also concerned that the research should be morally adequate in feminist terms, in that it would not contribute to further oppression of women. Ways in which I aimed to achieve this centred on the women's voices being actively heard in the final document. All names used in this thesis are pseudonyms.

This section has been concerned with the feminist theoretical framework within this research is situated and the pluralistic mixed methods approach to the research and ensuing ethical considerations. The following section is concerned with the data collection methods used in the sequential exploratory design of the study.

3.4 Methods

The data collection tools used were derived from clinical experience, theory as discussed in the previous sections of this chapter, and most importantly were informed by the experience of the women involved as the research developed. They allowed for reflection on the past, description in the present and planning for the future. Congruent with an exploratory sequential mixed methods approach (Creswell and Plano Clark, 2007, p. 121) the research methods continued to evolve as the research progressed. As identified in Section 3.2, a pragmatic approach to data collection was employed as determined by the research questions asked.

The methods used for data collection are outlined in Figure 3.1. As a sequential exploratory mixed methods approach is utilised for data collection – all of the stages contributed to answering the research questions below.

- What do women describe as stressful in relation to their insulin treated diabetes?
- What impact do these stressors have on women's lives?
- How do women with insulin treated diabetes interpret and manage their lives?

The recruitment of participants, methods of data collection and results relevant to the sequential nature of the research process will be discussed in each section for the focus groups, survey, and interview and journal keeping stages. This is in keeping with the way in which the methods were iterative and developed from each other.

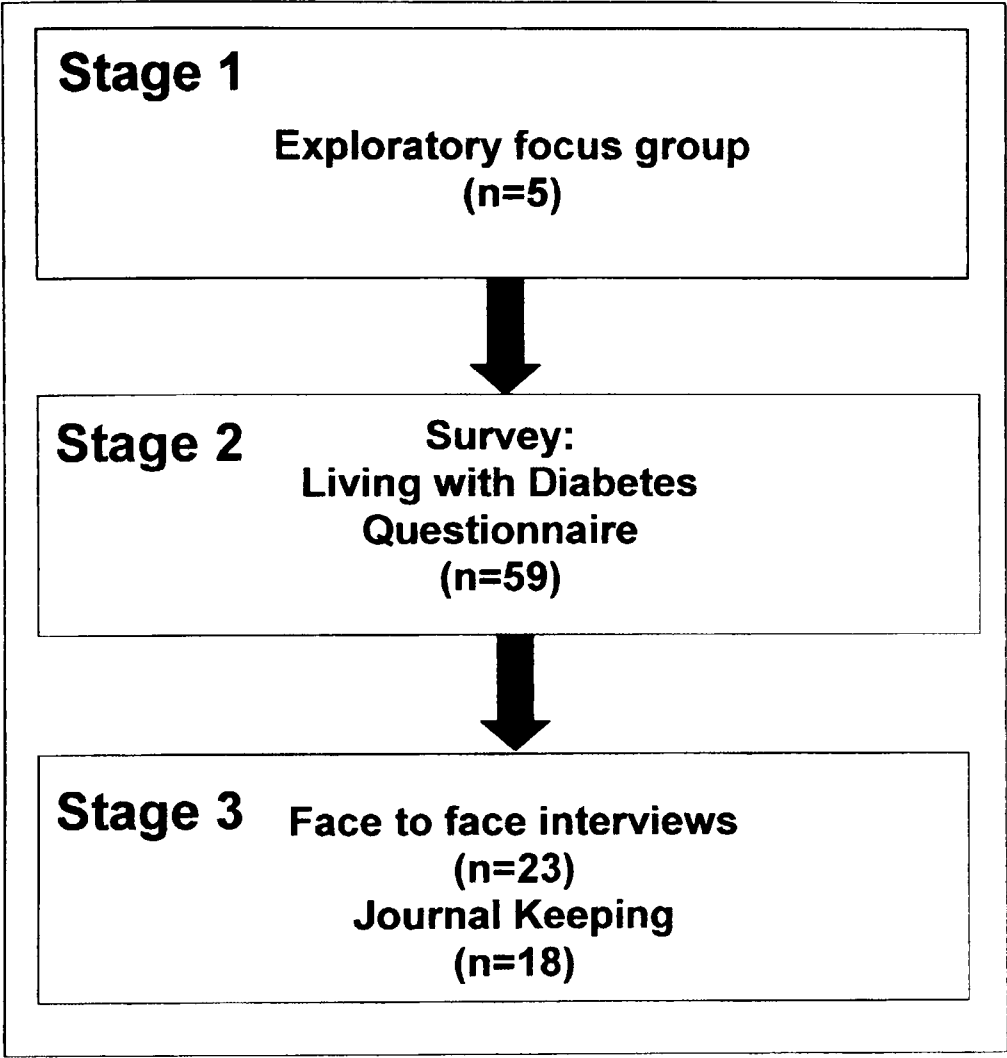


Figure 3.1 Study design flowchart.

3.4.1 Overview of research methods

Sequential data collection occurs in stages, rather than concurrently. The initial stage of data collection in this study was qualitative (focus group consisting of five participants). Following this, Stage 2 of the data collection consisted of a quantitative survey design using a newly-developed *Living with Diabetes* questionnaire, based on the findings of the focus group. Fifty nine women participated in this stage of the research. The survey was used to confirm that the results from the focus group were applicable to a larger group of

women, as well as to identify the participants for the final stage of the research process. This final stage was a further qualitative stage of interviews and journal keeping and twenty three and eighteen women took part in these stages respectively. In exploratory sequential mixed methods research the qualitative and quantitative data collections are related in that subsequent stages build on former ones, and one type of data is given priority over the other. In this thesis priority was given to the final qualitative stage as this was congruent with the research questions posed and the exploratory nature of the research.

Using the theoretical and methodological issues discussed in the preceding sections as the basis for the research methods, the fieldwork for the study took place over a period of approximately 18 months, from placing an initial call for volunteers to the end of data collection.

3.4.2 Obtaining a sample

The overall sampling strategy is one described by Patton (1990) as, mixed purposeful, that is a combination of methods were used to obtain an information rich sample. A small, self-selected sample was required for the focus group, all of whom lived within easy travelling distance of the venue which was a modern town with a population of over 200,000 in England. A larger self-selected sample was required for the survey stage. A smaller homogenous group of women in midlife was selected for interviewing and journal keeping. Specific sampling strategies will be discussed in the appropriate section for each stage of the research.

3.4.3 Stage One - Focus Group (n=5)

Focus groups have previously been used to explore health beliefs and practices in diabetes care (Anderson et al., 1998; Maillet et al., 1996; Price et al., 2009; Richards et al., 2006). The purpose of the focus group in this research was to develop the key issues

that might be of importance to women with diabetes, to evaluate the inclusion of areas identified through the literature review and to contribute to the development of a postal questionnaire for the second survey stage of the research. I tried not to define the experience of the women in advance and felt that an externally defined structure was inappropriate. The research questions were based upon the literature search and my professional experience, and a topic guide was developed from these.

Powell et al. (1996, p. 499) describe focus groups as '*a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research*'. When used within a feminist framework, Reinharz (1992, p. 222) describes them as face to face interactions with under 12 people that are time limited. They allow for a one off discussion of a topic, with the researcher asking a few questions and listening to the ensuing discussion which is usually tape recorded and transcribed prior to analysis. The interaction as well as the content provides a focus for analysis, where meanings may be co- constructed among the group members (Wilkinson, 1998a). Morgan (1988, p. 12) describes this process as '*explicit use of group interaction to produce data and insights that would be less accessible without the interaction found in a group*'.

In feminist terms, focus groups are a useful method for participants to voice their own constructed meanings and may have an empowering effect on those who take part. The researcher has less control of the research environment than in a one to one interview situation. Harrison and Barlow (1995, p. 12) explained this by saying that '*active participation empowers group members who feel that their views and experiences are valued*' and the researcher has potentially less power and influence in a group than in a one to one situation, as the group members have the potential to take control of a subject. Wilkinson (1998b) suggests that a group situation may enhance disclosure (although it is impossible to know what is not disclosed), more natural language is likely to be used and new information is provided (which was one of the purposes of this group). She describes group discussion of personal experience as engendering a

therapeutic and conscious raising effect, and although this was not the primary purpose of the focus group comments were made that it was a welcome and unusual opportunity to discuss issues relating to diabetes. The principles of Kitzinger's (1995) description of the non-discriminatory nature of group discussion were adhered to. Participation was encouraged, as was providing an opportunity for exploring issues defined by the research participants in their own words, taking an active part, in an atmosphere of mutual support. However there are also limitations to the use of focus groups. There may be those who feel discriminated against within the group and if there is inadequate facilitation the predominant view may silence any dissenting voices. Complete confidentiality cannot be assured as a focus group is non-hierarchical in nature and the power and control does not rest with any one person. Quality of data may be improved as a result of group members asking for clarification of issues raised and building upon responses. In terms of efficiency, data may be gathered from more participants within a given time scale, but fewer questions may be asked than in an interview situation. The presence of more than one person is more likely to reveal multiple understandings and meanings than in a one to one interview (Morgan, 1988).

Participants

The women in this study were recruited as a purposive self selected sample. An advertisement was placed in a newsletter for employees within an adult learning institution which was circulated to approximately 5000 people. The decision to access participants from an adult learning institution was based upon the geographical location of the employees' workplace in relation to my research base, and convenience for participants to attend the focus group in their lunch break with no additional travelling involved. It was expected that a newsletter with a circulation of 5000 would be sufficient to identify a number of potential participants. All replies were acknowledged and asked for contact addresses and times available for attending a discussion group. As the issue was the August 2000 edition, it was envisaged that some people could be on holiday and

not see the piece until September 2000, so an 8 week period was allowed for replies. At the end of the 8 week period a letter (using headed notepaper) was sent to those who had replied thanking them for their interest to date, explaining the aims of the study, how the results would be disseminated, funding of the research, issues of ethical approval and confidentiality and arrangements for the group meeting. A consent form was enclosed (see Appendix 1). An envelope and reply paid label were enclosed for their return, and for all stages of the study requiring a reply. The aim of sending out the information sheet and consent forms in advance was to provide the women with the opportunity to read them beforehand so that they had an idea of the aims of the study and to allow time for an informed decision to be made about taking part in the study. All six women who replied to the advertisement were invited to attend the focus group – five accepted.

All women who took part in the focus group have been given pseudonyms in order to protect their identities in keeping with the ethical aims of the study.

Profile of the participants (see Table 3.1)

All the women were of white British Caucasian extraction and all lived within the United Kingdom. The women were aged between 21 and 50 years. One was aged between 21 and 30, one between 31 and 40, and three between 41 and 50. All of the women were in full time work. Four worked for the same employer, one in an administrative capacity, one in a professional capacity, one in purely management and one shared her time between teaching and management. Two of the women had caring responsibilities – both for an elderly parent. Three of the women did not have children. One of the women had children living at home, and one had children and step children who had left home. They all lived with a partner.

Table 3.1 – Social profile of the 5 women in the focus group

Name	Age Band	Work	Caring for family members other than children living at home	Caring for children at home	Children left home	Household members
Verity	41-50	Full time Management	Father	No	Yes	Partner
Caroline	31-40	Full time Manager/Teacher	No	Yes	No	Partner Children
Gemma	21-30	Full time Administrative	No	No	No	Partner
Sylvia	41-50	Full time Administrative	No	No	No	Partner
Enid	41-50	Full time Professional	Mother	No	No	Partner

Table 3.2 – Diabetes profile of the 5 women in the focus group

Name	Age Band	Duration of diabetes in years since diagnosis	Duration of insulin treatment in years	Family members with diabetes
Verity	41–50	25	1.5	Grandmother, parents, aunt and sister
Caroline	31–40	8	8	No
Gemma	21–30	13	13	No
Sylvia	41–50	16	16	Parents
Enid	41–50	Not known	Not known	Not known

Enid declined to give information regarding her diabetes profile. This data was collected after the focus group had taken place, and she did not wish to continue to take part in the research following the focus group. There was variation in the amount of time the focus group participants had had diabetes, ranging from 8–25 years (mean duration 15.5 years), indicating that the experience of living with diabetes ranged from those diagnosed during childhood, to those diagnosed in adulthood. For those women who had been diagnosed in childhood/early adulthood, it is reasonable to assume that they had Type 1 diabetes. However, the picture is less clear for those diagnosed later in life, as they may have had either Type 1 or Type 2 diabetes. However, for the purpose of this study this is not relevant, as it is the treatment of the condition with insulin and the associated outcomes that are of interest.

Three of the four women who took part in the focus group had been treated with insulin since diagnosis; with Verity only being treated with insulin for one year despite having had diabetes for 25 years, suggesting that for her the experience of managing insulin treated diabetes was only a part of her total experience of living with diabetes. The mean duration of insulin treatment was 9.6 years. Two of the women had no other family members with diabetes. Verity's parents and a sibling had diabetes, as did her grandmother and an aunt. Sylvia's parents both had diabetes.

Implementation of the Focus Group

The focus group discussion took place in early November 2000. The aim was to identify key areas for inclusion in the research, identify gaps and wider issues and to refine and develop questions for use in future questionnaires and interviews. I was very concerned that the issues I asked about in relation to diabetes were important to the women themselves, rather than being totally constructed by me, as someone who did not have diabetes. A lunchtime session within the adult learning institution was arranged, as this allowed women to attend during their lunch break and lunch was provided. Copies of the information sheet, consent form and questionnaire, were available in case the originals

were forgotten. The aim was to create an environment that was safe and not too formal, with a view to there being an atmosphere that was conducive to discussion in terms of being friendly, open, non-judgmental and of mutual respect (Creswell, 1998; Wilkinson, 1999).

Implementation of the focus group consisted of three stages – preparation, introduction and discussion, and my role as a moderator was to facilitate discussion in a nondirective and unbiased way using predetermined questions (Kingray et al., 1990).

Preparation – this included preparing the physical environment, organising refreshments, checking of equipment and providing tissues in case any of the women found recalling their experience an emotional event. The furniture was arranged into a circle to allow equal participation.

Introduction – this consisted of the giving of background information in terms of explaining how the group would function and to put the group members at ease with refreshments being served, followed by discussion of the experience of living with diabetes. Interpersonal skills similar to those used in conducting interviews were used such as asking short, single open ended questions, reflecting questions back and probing to check interpretation, inviting clarification, expansion and explanation of terms, use of non verbal communication and silence. Projective techniques were used, such as visualization of the future, and an open-ended question asked at the end. I attempted to have some eye contact with each group member and to make sure that everyone had the opportunity to speak. Although some women were initially apprehensive about contributing to the discussion, everyone made valued contributions to the discussion as the group progressed. I aimed to maintain an open non-judgmental attitude throughout the session.

I introduced myself and the purpose of the study and the women were invited to introduce themselves. The group members were asked to introduce themselves for three purposes – for identification from the tape when transcribing, to gain some background

information about each person, and to give everyone a chance to speak in an attempt to put them at their ease prior to discussing the key issues. I explained that the session was to be tape recorded to avoid the need for note taking and to allow me to concentrate on what was being said and to facilitate the discussion. No one stated that they had any objection. I asked if only one person would speak at a time for ease of later transcription. When transcribing there were times when the recording was unclear, and there was a gap when the tape was turned over between sides, but in general the recording was satisfactory for transcribing purposes. An assurance of anonymity was given and the women assured that it would be issues, not individuals, who would be identified. The importance of confidentiality between group members was also emphasised and a reassurance that people often have a variety of views, all of which are valid, and that there were no right or wrong answers.

Discussion – A list of proposed questions had been prepared to guide the focus group discussion (Table 3.3) based on my previous clinical experience and on issues identified through the literature review. It was not intended to be prescriptive or limiting. The questions were open ended and general in nature, free from jargon, and specific areas for discussion were not identified. Questions were asked in response to the issues raised by the women themselves in line with feminist philosophy (Wilkinson, 1998a). Part of the discussion included the consideration of items that might be included in a postal survey on stress and diabetes, which was identified as a *Living with Diabetes Questionnaire* (LWDQ). At the end of the session the women were invited to ask questions. I attempted to answer these to the best of my ability and the women were given the number of the Diabetes UK Careline, a confidential information service, at the end of the group discussion and were encouraged to contact me, as an alternative, if there were issues they wished to discuss further. We agreed that I would produce a draft of the LWDQ which would be distributed to a wider group of women as part of the larger study and send it out to them for further comment. All women who took part were

Table 3.3 Questions for focus group discussion

1	What words come to mind when you think about living with diabetes?
2	If you had to tell another woman what the most stressful part of having diabetes was, what would you say?
3	How would you describe the most stressful thing in your life related to your diabetes?
4	What things are particularly difficult for you?
5	What other things do you find stressful about having diabetes?
6	It would be helpful if you could talk about these in relation to your everyday life i.e. how do you think they affect your daily life and work? Perhaps you could give examples?
7	What parts of your daily life have changed since diagnosis? Perhaps you could give examples?
8	What effect do you feel that these issues have upon you?
9	How do you think they affect your relationships with other people?
10	How would you describe stress-what does it mean to you?
11	How do you feel when you are stressed?
12	How do you react to feeling stressed?
13	What effect does the stress have on your diabetes and the way you manage it?
14	How do you visualise your life in the future in relation to living with diabetes?
15	Is there anything about your experience of living with diabetes, which you would like to share, that I have not asked about?

thanked for their contribution either by e-mail or post. A transcript of the discussion was sent to each woman, with pseudonyms for security, and comments were invited. None were received.

The discussions generated within the focus group were audio-taped, listened to and fully transcribed, and the women’s accounts interpreted to inform subsequent research design.

Results

Thematic analysis (Braun and Clarke, 2006) was used to analyse the focus group transcript as this is a flexible analytical method that can be applied across a range of theoretical and epistemological approaches. An initial thematic analysis of the transcribed group discussion identified four sources of stress:

- Fear of the future and the development of the long term complications of diabetes, and their potential impact on their lives.
- Impact on daily life and the current effect of diabetes affecting their ability to carry out their social roles.
- Health care professionals and their influence on the control of diabetes and the relationship that existed between them and the women.
- Other people and the relationship between them and the women.

Focus groups were not used in the subsequent stages of the research process, due to the wide geographical distribution of the research participants. The four sources of stress identified by the focus group participants were incorporated into a postal survey, which comprised Stage Two of the study.

3.4.4 Stage Two – Survey (n=59)

Postal questionnaires are described by Robson (1993) as being efficient in terms of researcher time, effort and cost to administer to large numbers of people spread over a wide geographical area, as participants were in this study. Closed questions are quick to code and to analyse, but there is no check on the rigour of responses, as there is often no other contact with the respondent. Care is necessary in the design of the questionnaire, in terms of avoidance of ambiguity, and the use of clear language and instructions. A postal questionnaire was chosen, given the wide geographical locations, as it would allow for

inclusion of all women who had agreed to take part in the study, allowing for access to a wide range of information, which would be relatively straightforward to code and analyse.

Obtaining a sample

Women for the survey stage were recruited by means of an advertisement which was placed in the October 2000 edition of a newsletter circulated to adult learners, rather than employees, of an adult learning institution which had a circulation of approximately 171,000. This was the same learning institution referred to in the previous focus group stage of the study, but the focus group participants were not included in subsequent stages. This group was chosen as the newsletter was distributed throughout the United Kingdom and it was envisaged that women would respond from a variety of geographical locations and social contexts. Those that responded (n=67) were contacted by return to say that I would subsequently send out a questionnaire, to which 59 responded (88% response rate).

Living with Diabetes Questionnaire (LWDQ) (n=59)

Using information gained from the focus group members, a '*Living with Diabetes Questionnaire*' was designed and mailed back to these participants for comments. In keeping with the methodology of the study, a combination of open and closed questions was used in the design of the questionnaire, allowing for quantitative and qualitative analysis. Areas identified were age, ethnicity, work, family structure, roles, relationships, diabetes history and care/support structures, general and diabetes related stress. Further revisions were made in response to the focus group comments and a final version was then used (see Appendix 2).

Results of Stage 2

The data obtained from this stage was used to:

- Identify the extent to which stress was an issue for women living with diabetes
- Identify the sample who were included in Stage 3 of the study (interviews and journal keeping)
- Describe the characteristics of the sample who were included in Stages 3 of the study.

The first two of these points will be discussed within this section, as they influenced the further sequential development of the study, with the third being discussed later in this chapter in Section 3.7.

Results from the questionnaire suggested that stress was an issue for women in relation to living with diabetes:

- 63% reported that living with diabetes was stressful
- 69% identified diabetes as affecting their daily life and work
- 73% perceived stress to affect their diabetes management.

As a result of this it was decided to select a group of women from those who had responded to the survey to interview in-depth. They would also be provided with journals within which to record their experiences of stress in relation to living with diabetes for a period of three months. From the data obtained from the *Living with Diabetes* questionnaire it was identified that some women were engaged in a variety of roles and responsibilities, some multiple relating to partnerships, parenting, caring for elderly relatives, employment, in addition to having diabetes. These were women in midlife, which I defined as being between aged 41 and 60. Women within this age range also comprised the largest group of women who had responded to the questionnaire (48%). Twenty eight women were identified in this age range and three were excluded for the following reasons. One lived abroad; one had died since her initial response although her husband offered to talk to me. (I declined this offer, but asked permission to use

information she had already given, to which he agreed); one was excluded on ethical and moral grounds, as her questionnaire responses led me to be concerned about her emotional state and attitude towards her diabetes and I was concerned that taking a further part in the study may have negatively influenced this further. She had few roles and appeared to have few support networks. The 25 remaining women had all completed *Living with Diabetes* questionnaires. These women were contacted and asked if they would be willing to be interviewed face to face.

3.4.5 Stage Three -Face to face interviews (n=23) and journal keeping (n=18)

This stage of the research study involved the in-depth collection of data using one to one interviews and journal keeping, and was the stage of the sequential data collection which was given the highest priority due to the nature of the research questions relating to the understanding of the experience of living with diabetes. A pilot study of this stage involved 2 women, who were from the sample of 25 who were not excluded, and was undertaken prior to the main study, leaving a sample of 23 for the main part of Stage 3.

Interviews (n=23)

Accounts of the use of interviews in qualitative research abound in research methodology textbooks and are probably the most common data collection tool used in such research (Bowling, 1997; Burgess, 1984; Denzin and Lincoln, 2000; Kvale, 1996; Reynolds, 1972; Robson, 1993; Silverman, 1983; Smith et al., 2009; Taylor and Bogdan, 1984). They range from being structured to unstructured in design. In keeping with the nature of this research, a feminist interpretation was applied to the conduct of interviews. Anderson (1991), drawing upon her work with women with diabetes, suggests one way of immediately empowering and making a difference to the lives of those taking part in the research is to respond positively to requests for information from the women within the interviews. As this research rejects the boundaries between objective and subjective

i.e. quantitative and qualitative methodology and sees them as complementary, accusations of bias, based on a scientific approach are inappropriate for data collected in the stage of the research using interviewing as a method (Lincoln and Guba, 1985; Yardley, 2008). Alternative criteria may be used to judge the quality of the research, but need to remain open to re-interpretation if change occurs or novel approaches are utilised (Sparkes 2008, 2009). Responding to such requests provides opportunity for a more equitable distribution of power between the researcher and the research participant and the information given and received can be used by the women to take control over their lives. There are few opportunities within diabetes care to discuss the experience of living with diabetes, and it is recognised that there is a lack of counselling and psychological support for people with diabetes. The interview situation and the completion of journals allows for reflection and (re)construction of their experience of living with diabetes. Therefore knowledge is constructed through the interaction, with both parties affecting and being affected by the process.

The interview process can be described as an interaction used to interpret the meanings women give to their world and entails asking questions and listening to responses. According to Oakley (1981), in feminist terms it is desirable that the relationship is two way, non hierarchical and occurs in an atmosphere of mutual respect with both the researcher and the participant being willing to invest some of their own identity. The researcher becomes much more than an instrument of data collection. Qualities within such personal relationships have been described as reciprocity, friendship and collaboration (Ribbens, 1989). In her qualitative study of clergymen's wives, Finch (1993, p. 74) described herself as the '*friendly guest*' not an '*official inquisitor*'. Similarly Reinharz (1992, p. 27) refers to the interviewer as a '*friendly stranger*'. Oakley (1981) describes the shared experience of being a woman within the research process. Although I shared the experience of being a woman within the same age range of the women interviewed and with a similar cultural pattern, I could not share the perspective of having diabetes. I was also a health care professional, and I did not divulge this unless I was

specifically asked about my motives for doing the research, or I was asked a question relating to my professional knowledge during the interview. The potential for tension between the role of researcher and clinician will be revisited in Chapter 8.

The rationale for the use of interviews was that it would give access to information, in a private unhurried setting, which was not accessible from a questionnaire. I followed a semi structured interview schedule, and always started and ended the interview with an open-ended question. This gave the women the opportunity to talk about what was most important to them. It was not always appropriate to ask some of the questions, they were not always asked in the same order and the progression of the interview was led by the women themselves. This would have been problematic methodologically if the aim of the study was to make generalisable inferences, but this was not the case. This approach was consistent with the avoidance of exerting control over another, and women were asked where they would prefer to be interviewed. Although I had an agenda for the interview, the women chose what they wished to disclose. I was aware of the fact that I had privileged access to private information and was concerned that it should be put to good use, after it left the control of the research participants and that the emphasis should be given to their own words. I explained that they had the right to terminate their involvement in the research at any time and I would not use any information without their permission.

Birch (2000) discusses the boundaries between researcher and therapist as becoming blurred, and the similarities between feminist interviews and counselling interviews. I was very aware of this, and tried not to slip into a counselling role as this was not the role of the study. I was also aware of the potential for participants to disclose distressing material in such an encounter that may or may not be related to the study in question.

Pilot interviews

One woman, who was unable to attend the focus group discussion but had completed the *Living with Diabetes* questionnaire, was selected to pilot the interview. During this interview it became apparent that some questions required rewording and clarification, and some needed to be removed completely. I decided to do another pilot interview with a woman selected at random from the 25 women selected for interview. Both of these interviews took place within an hour's travelling distance of the adult learning institution for ease of access. Following this interview, an amended set of guidelines for interview was devised (see Appendix 3). Questions relating to the potential impact of diabetes and lifestyle on life in the future were removed, as I felt that this may raise issues and fears for the women, which I was not in a position to address in a therapeutic way, as did a question asking for reflection on how life may have been different. A list of stressful life events had been originally included, but this was felt to be too prescriptive.

Main interviews

Following the pilot stage, all 23 of the women in the midlife age range who had returned the *Living with Diabetes* questionnaire and who had not taken part in the pilot study were then interviewed and given a journal to complete for a period of 3 months. A confidentiality agreement (see Appendix 4) was devised for all participants being interviewed, in addition to the existing consent form, referring to ethical scrutiny, confidentiality and ownership of the audiotape. The intention was to follow a topic list rather than an interview schedule resulting in a combination of an informal conversational interview and a guide for a semi-structured interview. It was not a totally unstructured interview as there was a focus i.e. living with diabetes, but there was flexibility in terms of breadth and depth. The goal of the interview was to enter into a dialogue about lived experience, in order to address the research questions identified in Chapter One. The questions were structured around the categories suggested by Robson (1993, pp. 234–235) i.e. introduction, warm up, main body, cool off and closure.

Interviews took place between June and September 2001 and took between one and five hours to complete. Geographical locations were in England, Wales and Scotland, and varied from inner city housing estates to remote rural and coastal locations. All interviews took place in the women's own homes, apart from two. One was in an office at the woman's workplace, and the other at the house belonging to the daughter of the woman, for reasons of privacy. One woman initially said that she would prefer not to be interviewed at home for domestic reasons, but was in fact interviewed at home when her husband was out. She had initially not responded to my request for an interview, as her husband had not passed on the message to her. Two visits were required to repeat one interview as the woman had an appointment, and the interview was not complete by that time. Two others were completed by telephone, one of these on two occasions due to the woman's time commitments. All interviews except one were conducted inside, the one outside being in the garden, at the woman's request. Most took place with just the woman present, although the husbands of two women remained in close proximity for the bulk of the interview. Opportunities were taken to discuss relationships, when they either left the room or closed the door. Three women suffered from obvious physical difficulties which were either related to other long term conditions, or the long term complications of diabetes.

All interviews were tape recorded, but unfortunately on two occasions the tape failed for no obvious reason. I decided not to attempt to repeat the interviews, as the women would have knowledge of the questions asked, and I felt it would be an imposition on their goodwill. I had in fact taken some notes during all of the interviews. Most women had expected me to do so, and usually directed me to a table for ease of writing, and did not appear to find it intrusive. I explained that it was a back up in case the tape failed, and would act as a prompt for me to return to issues they had raised. These notes were supplemented as soon as possible after the discovery that the tape

recording had failed. Other obvious gaps in tape recording were when the tape was turned over or women started talking about their experience before the recording commenced.

The interview guidelines were used in all interviews. Questions were not always asked in the same order, the conversation being led by the women themselves, depending upon their responses to the request for them to tell me about their experience of living with diabetes. Prompting techniques were used where necessary. Interviews always commenced with checking with the women if any information on their *Living with Diabetes* questionnaire had changed. We looked at the questionnaire together, giving a common point of reference, and opening conversation and the interview progressed from there. All women were given the number of the Diabetes Careline again and a contact card for me. Transcripts of interviews were not returned to the women, as they were not just their own constructions of reality, and I was concerned how they may be affected by revisiting some of the issues. There was also the issue of confidentiality within their homes, if a copy was returned. All women were asked if they would like the tape returning to them; none did.

Journal keeping (n=18)

All the women who were interviewed were asked to keep a journal during the three months following their interview. Journals were used as a method of providing an insight into the experience of the women and were as close as I could get to observing what happened during that time. They could also clarify and supplement the spoken word, and contain both private and public information. Of course, I could only see what the women allowed me to look at, and in a way that was constructed by them. They would be completed from the subjective perspective of the author, who had control over the content and presentation of the content, which would become a permanent record. Robson (1993, p. 254) refers to them as a '*proxy for observation*'. Zimmerman and Wieder (1977) describe the use of diaries in conjunction with an interview method, but

the diaries are given *before* the interview takes place. This order was reversed in the current study because I wanted to begin to develop a relationship of trust with the women before I asked them to do something which could potentially cause them to reflect on sensitive issues. Bolton (1998, p. 46) suggests that writing can be a therapeutic activity, and may help individuals face, understand and come to terms with their experiences. Writing in the form of letters has also been documented in women with Type 2 diabetes (Kralik et al., 2000). Plummer (1983) describes 3 ways of keeping diaries i.e. as an unstructured daily diary, a log and the diary/interview strategy previously described. The use of the journal in this research is a hybrid of these strategies. Diaries have been used in both feminist and health research (Bowling, 1997; Elliott, 1997; Personal Narratives Group, 1989), with a view to making the hidden visible.

Use of the journal with the women constituted what Bell (1998, p. 73) defines as '*a solicited diary*', a primary document, given for the purpose of the research, with the opportunity to present the data in the way that was the most suitable to them and was non-prescriptive in nature. It also offered an opportunity for debriefing following the interviews.

All 23 interviewees as well as both of the women in the pilot study were asked to keep a journal for a period of 3 months. They were given a hardback notebook, with a brocade cover. I did not want the book to resemble a diary for the recording of blood glucose results that is often given out in diabetes clinics, both in hospital and community settings. I did not call it a diary, again because of the medical connotations, and I did not want the women to feel that they were under pressure to complete it on a daily basis. An assurance of confidentiality was again made, and it was explained that it was not a requirement to enter blood glucose results unless they particularly wanted to do so. The paper was blank, with no lines. The reasoning for this was so that the women felt free to make their entries in which ever way that they wished, the only constraint being the size of the book (A5). Guidelines for completing the journal were pasted into the inside cover of the journal, together with contact details if there were any queries. These consisted of

suggestions of the types of entries that could be made, and a reassurance that there was no right or wrong way to complete the journal. I arranged to contact them before the end of the 3-month period to check their progress. When I telephoned, I explained that I was not checking up on them, but was contacting them to see how useful they had found the journal and to answer any queries they may have. A letter was sent requesting the return of the journals, and a questionnaire enclosed asking if any entries had been made in the journal and asking for information about the ease or difficulty of completion. Prior to undertaking the main set of interviews this was expanded to ask for information about where the journal had been kept, and the relation of the entries to stressful events.

Eighteen of the 23 women interviewed returned their journals. They had the choice of whether and/or how they would make entries. In keeping with the philosophy of the research the power was handed over to the women in this way. Both verbal and written guidelines were given about completion of the journal, and alternative ways of collecting the information given to those who felt apprehensive e.g. Dictaphone.

3.5 Analysis

The interview data was analysed using interpretative phenomenological analysis (IPA), utilizing Atlas ti qualitative data analysis software for coding and development of themes. The data obtained from the journals were used as descriptive examples to illustrate the stories told, and were incorporated into the resulting narrative account.

3.5.1 Interpretative Phenomenological Analysis (IPA)

The theoretical position of IPA is derived from Husserl's view of phenomenology, the hermeneutics of Heidegger and symbolic interactionism (Denzin and Lincoln, 1998). Each of these perspectives is of relevance to this study. Husserl is concerned with the construction of a philosophical science of consciousness and with an individual's personal perception of experience. Heidegger recognises the centrality of the researcher to the

analytical process as an interpreter and symbolic interactionism is concerned with meanings that occur in, and as a result of, social interactions, and asserts that they can only be obtained through a process of interpretation with its associated creativity and freedom. However, interpretation may be limited by the participant's ability to articulate their experiences and the researcher's ability to reflect and analyse.

Smith (1994) sees IPA as having a dual nature – both to explore participants' views of the world by adopting the '*insider perspective*' described by Conrad (2000), and also recognizing that research is a dynamic process, with the researcher's own conceptions influencing the interpretation of that world. Context and language are recognized as being important, as in narrative and discursive approaches, but here the similarity with discourse analysis (DA) ends. DA sees the relationship between talk and cognition as being problematic, DA takes the epistemological stance that it is not possible to access an individual's cognitive inner world and instead examines the role of language in describing experience. IPA recognizes a link between cognition and verbal response, and is concerned with how meaning is ascribed to experience. There is an acceptance of bodies and illnesses as real entities, rather than as social constructions and the assumption is made in this study that women think about their diabetes (a defined bodily state), and their responses relate to these thoughts. There is a link between the physical condition, cognition and verbal response. IPA is particularly suitable for studying health issues because of their human embodiment and the very different ways in which the same illness is experienced.

IPA focuses on experiences, understandings, perception and views of personal experiences, rather than social processes as in the case of grounded theory (Glaser and Strauss, 1967). It is useful for understanding the constructed, as opposed to the biomedical nature of illness. IPA is an idiographic (beginning with the particular and moving to the broad) qualitative methodology that involves the analysis of verbatim transcripts derived from in-depth semi structured interviews (Smith, 1994; Smith and Eatough, 2007; Smith et al., 1999; Smith, 2009; Smith et al., 2009) or other sources of

narrative data. In line with other phenomenological approaches, the aim is to facilitate the telling of experiences, rather than to check the preconceptions of the researcher.

Although simple in its approach, IPA is paradoxical in that it allows the researcher to deal with complexity within a subject area. It offers a research tool for understanding health care and illness from the perspective of the service user. Meanings are elicited from biographical stories of individuals within their own social realities. In this way, understanding of the complexity of biopsychosocial phenomena are facilitated which in turn has the potential to inform clinical practice (Biggerstaff and Thompson, 2008). IPA may produce studies of theoretical and practical importance. Some studies make use of single cases, whereas others use sets of cases, but numbers remain small to allow for depth of analysis as discussed in Section 3.5.2.

The main aim of IPA is to explore in detail the participant's view of the topic under investigation and to capture how individuals perceive and respond to their experiences. It is concerned with the meanings that those experiences hold for them. Particular individual's perceptions are captured, together with responses to their experience. The aim is to gain an understanding of the content and complexity of such meanings, rather than to take measures of frequency, although descriptive statistics can be incorporated into the resulting narrative, to increase acceptability to some audiences. This approach has been used within this thesis by the use of descriptive statistics from questionnaire data, and descriptive examples have been used from journal data to 'tell the story'.

IPA was initially developed for use within the field of health psychology, and it was recognized that there was a convergence between psychology and medical sociology (Smith, 1994). It has been used in studies examining patients' perceptions of chronic disease e.g. stroke, back pain (Hunt and Smith, 2004; Osborn and Smith, 1998). It is becoming used in the field of diabetes (Morris et al., 2005), but no studies have been found that specifically relate to stress and diabetes.

3.5.2 IPA method

Research methods in this approach usually focus on semi- structured interviews, although written accounts, such as journals in this study, may also be used. Sample size may range from a single case (Smith, 1994), to larger samples, although often consist of no more than 10–12 participants (Osborn and Smith, 1998). However the approach can be adapted to the number of women interviewed as in this study in this study (23), by looking at a small group in detail and broadening the findings to a larger group, and by identifying shared themes for the group as a whole (Reynolds and Prior, 2003).

Purposeful homogenous sampling was employed – all white Caucasian women in midlife living with diabetes in the case of this study. Interview data was transcribed verbatim, including the questions asked. Although an interview schedule was used, it was implemented in a flexible way, with the sequence of questioning being determined by the responses given, and topics introduced by the participant being probed.

The different accounts, in the form of interview transcripts and journals were examined in detail to elicit perceptions of individual women, and the processes and outcomes resulting from them. No claims for representativeness or generalisability are made. Instead, particular cases are represented to gain a more detailed picture of a phenomenon i.e. stress experienced in relation to living with diabetes in this case. The aim here is to add the knowledge gained from personal experience to that generated by the dominant medical discourse – to address inequalities in the balance of power and to inform and influence clinical practice, perhaps by suggesting and guiding changes in practice. In this approach, the importance of taking account of individual experience is stressed, congruent with the empowerment approach in diabetes care.

The IPA methods used in this study are congruent with those used in other IPA studies identified in Brocki and Weardon's (2006) systematic review of the use of IPA in health psychology research, in relation to the use of semi – structured interviews and purposive and homogenous sampling. As identified in the following section, moving from

descriptive to interpretative analysis and using methods of assessing rigor other than validity and reliability are also compatible with using IPA.

3.5.3 IPA analysis

Analysis of the data is a product of reflection on the part of both the participant and the researcher, with the aim of producing a detailed account of what an experience means for a particular person, or group of individuals. The meaning for an individual at a particular time is represented, rather than a description of diabetes itself. The *frequency* of themes is not necessarily always of importance, but the *strength* of a construct may be. A way of determining this is whether the issue is raised by the individual or the researcher, and the way in which it is described e.g. through the use of emotive language and metaphors. Themes may not be selected on the basis of their prevalence within the data, but because of their potential to illuminate other aspects of the data. The richness of some passages may serve to highlight particular themes. Convergences and divergences, uniqueness and commonality, may be found within, as well as between, accounts, and a wide range of themes emerging may represent the multidimensional nature of an individual's experience. This approach does not concentrate on relationships and associations between *individuals*, but rather between *themes and concepts* e.g. between control and stress. Findings are closely linked with verbatim material from the data in which they are grounded, and congruent with a feminist approach, the women's accounts are made visible and it is a democratic and participant centred approach. Findings are data, rather than theory, driven.

Analysis consisted of an initial systematic search for themes initially in one case, a search for connections between themes, a subsequent comparison and integration of themes across cases, and establishment of superordinate or major themes within and across cases (Smith et al., 1999). The aim was to produce theoretical statements from the data, which may be rich and divergent, which are true for all of the cases examined. These statements were produced, reviewed and modified from patterns and relationships

between themes within the data. A narrative account was produced, interspersed with verbatim extracts which illustrated and exemplified themes. These findings were then related to the existing literature. Methods of producing the analysed findings tend not to be prescriptive, as the emphasis is on interpretation rather than technique.

Using Smith's guidelines (1999), a list of themes was derived from interview data and sources identified, using Atlas ti software and a code produced for each theme using key words and abbreviations. The data was examined for relationships, and themes clustered together. This process was repeated for eight transcripts, and the remaining transcripts were examined for the occurrence of these themes and clusters. Text relating to themes and clusters was aggregated and transcripts and journal data examined for any missed themes which could then be incorporated. Patterns, connections and tensions were searched for within and between groupings, leading to identification of overarching, major and sub themes. Diagrams, notes and memos were incorporated into this process.

3.5.4 Rigor of the research process

All research involves the processes of data collection, analysis, verifying and presentation of results and must be able to demonstrate the quality and rigour of the methods used. For this thesis an alternative epistemological viewpoint is adopted in relation to issues such as reliability, generalisability and sample size. Rigour, transparency and coherence are alternative measures of the quality of the research undertaken and the context within which the work is undertaken is also important.

Concepts such as validity, bias and repeatability, usually found in quantitative research are not suitable for assessing the rigour of qualitative research, as reality is assumed to be multiple and constructed, as opposed to a single truth (Sandelowski, 1993) and the researcher is integral to the research process. In this study, there is an integration of creative expression of the results of the research and a phenomenological approach to analysis – both of which are individual in nature, making repeatability an

inappropriate measure of rigour. In addition, feminist research '*offers a way of conceptualizing reality that reflects women's interests and values and draws upon women's own interpretations of their experiences*' (Hall and Stevens, 1991) in contrast to the positivist view of universal, rather than multiple, reality which is supposedly value free. Feminist investigations are usually situated within broader socio political contexts.

Alternative terms in relation to feminist research have been documented by Hall and Stevens (1991) and reflect a more relevant and complete framework, and have been adopted for this research for that reason. They include *dependability*, which does not decontextualize the data and does not require repeatability across both observers and time. It is more concerned with methodological and analytical decision making trails. The concept of generalizability is also rejected on the grounds that human experiences are complex, although some information is transferable between contexts. *Adequacy* is a term that is described as being more suitable in feminist research than reliability and validity, as it implies that the research processes and outcomes are relevant and meaningful to the questions being asked, as in the case of pragmatic mixed methods research. *Critical reflexivity* as discussed in Section 3.1.3 may be used as a measure of the rigour of the feminist research process as it makes more explicit the participation of the researcher in the research process where knowledge is jointly constructed by the researcher and participants. *Credibility* is where explanations of women's experiences can be understood by both those taking part in the research process and those reading the report or thesis. However, returning transcripts to participants may not be without its problems as they will be read in a different temporal and spatial environment to when the data was collected, and participants will have had other experiences in between. *Rapport* within the relationship between researcher and participants is integral to qualitative feminist research and refers to an atmosphere of trust and openness. *Coherence* refers to the extent to which the findings of the whole and its constituent parts are consistent and are contextualized. Feminist research should also reflect the *complexity* of women's lives, located in both the context of their everyday lives and also in a larger socio-political

context. *Consensus* refers to the identification of recurring themes within the data, taking into account negative cases and divergent experiences and explanations, perhaps from differing data sources as in the case of mixed methods research. The *relevance* of the findings is key to feminist research in that women's concerns should be addressed and the findings should have the potential to improve women's lives. *Honesty and mutuality* are measures of rigor that underpin an ethical approach to feminist research, and adopt the view that this applies to both researcher and participant and also refers to the conscious monitoring of power dynamics within the relationship. *Naming* refers to the use of the women's own terms and generating concepts through the active voices of the women participants are heard in the research account. *Relationality* refers to collaborative working methods, either with the group being studied by the use of non-hierarchical and participatory methods, or with other researchers. These criteria broadly correspond to those described as relevant to interpretative phenomenological research – balanced integration (balance between the voices of the participants and philosophical explanation), openness (accounting for decision making), concreteness (usefulness for practice of findings), resonance (effect of reading study findings) and actualization (future realization of the resonance of the study findings (de Witt and Ploeg, 2006).

In addition to the feminist elements of this research, the findings have been expressed in a creative way by the use of poetic representation. For this reason, Richardson's (2000) criteria for use with Creative Analytical Practices (CAP) have been adopted for use in this research where a scientific and creative approach have been mixed together. These criteria are substantive contribution (how far the results contribute to understanding), aesthetic merit (are interpretative responses invited?), reflexivity, impact (is there an emotional and/or intellectual effect?) and expression of a reality (is it a credible account?).

The extent to which this study has met these criteria will be discussed in Section 8.1.

Richardson's (2000) concept of crystallization, as opposed to triangulation, is embedded within this research, where multiple perspectives are acknowledged and valued. A crystal has more faces than a two dimensional triangle, and how it is seen depends upon the perspective of the viewer, as well as the crystal itself. The research questions posed are complex and require multiple methods of data collection, analysis and representation of results.

There is no one 'correct' telling of this event. Each telling, like light hitting a crystal, reflects a different perspective on this incident.

(Denzin and Lincoln, 2005, p. 6)

This approach is also consistent with Denzin and Lincoln's notion of the '*researcher as bricoleur*', a quilter piecing together pieces of material that have no form as individual pieces, but together represent a version of a whole picture consisting of connected parts. Yet another analogy is that of Waddock and Spangler's (2000, p. 211) '*Humpty Dumpty*' problem, where problems are expected to be transformed from fragments into a whole within a single discipline or speciality, without taking other perspectives or dimensions into account. When other views are integrated, the whole picture may appear very differently to how it was originally perceived to be. Richardson and Adams St Pierre describe '*creative analytical processes*' (2005, p. 962), where the writing process and product are interrelated.

3.6 Writing up

This study was written up as a narrative account which presents elicited themes and statements, and is supported by verbatim extracts from the participants as clarification or exemplification (Smith et al., 2009). According to the data analysis methods of IPA the narrative presented in this thesis is a co-construction between the participants and the researcher (i.e. myself).

The aim for this thesis was to examine what stress in diabetes means, by looking in detail at how women talk about their experiences of living with diabetes in context, how they deal with them and the meanings they attach to them. Definitions and implications have been broadened and the potency and complexity of stress as a construct have been enhanced by the use of IPA.

Consistent with the principles of IPA analysis, the reader is provided with a holistic sense of the person which contextualises the analytical material. Smith et al. (2009, p. 106) state that *'what makes the analysis IPA is the fact that the group themes are still illustrated with particular examples taken from individuals'*. In this way, an idiographic focus on the voice of the individual is maintained, within themes identified for the larger group. The ensuing narrative represents a dialogue between the participant and the researcher that is reflected within the interweaving of analytical commentary and extracts from the raw data.

With the exception of the following chapter, each chapter commences with a statement outlining the nature of the major or superordinate theme(s) within that chapter. This is followed by analytical illustrations of how the theme is applied to participants within the study, including those of complexity and contradiction.

The interview data was analysed according to the principles of IPA. Although this analysis follows a more traditional style of analysis in qualitative research, elements of the *'bricolage'* remain. Not all of the pieces (themes) that contribute to the overall view (major theme) are of a similar shape or size. Some of these may appear to be less substantial in terms of content than others, but their intensity compensates for this. This intensity was manifested in ways such as the tone or volume of voice, or displays of emotion.

Examination of the data has identified a range of social roles and responsibilities of the women interviewed, which could be argued as being similar to women who do not have diabetes. What differentiated them from women without diabetes was that their

diabetes had an additional impact on their lives, which also in turn had the potential to affect diabetes in a cyclical manner, as will be examined in the subsequent data chapters.

Five superordinate themes were identified from the data analysis, which are:

- Diabetes as a nuisance
- Diabetes during daily life
- Diabetes at times of crisis
- Experiencing stress and maintaining control.

Experiencing stress and maintaining control are considered together in one chapter as they are interlinked and overarching themes throughout the thesis as a whole.

An overview of the hierarchy of these themes is shown in Figure 3.2. Constituent themes are also shown in this diagram and will be discussed in the appropriate chapter for each major (or superordinate) theme.

Chapter 4 is concerned with the theme of diabetes as a nuisance. It is divided into two parts, the first being concerned with poetic representation of the superordinate theme of diabetes as a nuisance, and the second with IPA analysis of its constituent subthemes.

Before moving on to Chapter Four, an overview of the characteristics of the women interviewed and given journals to keep is included. In keeping with the principles of IPA and a feminist approach to this research, a holistic cameo is also presented of each of these women, and this is presented at the beginning of Chapter Four. All names used are pseudonyms.

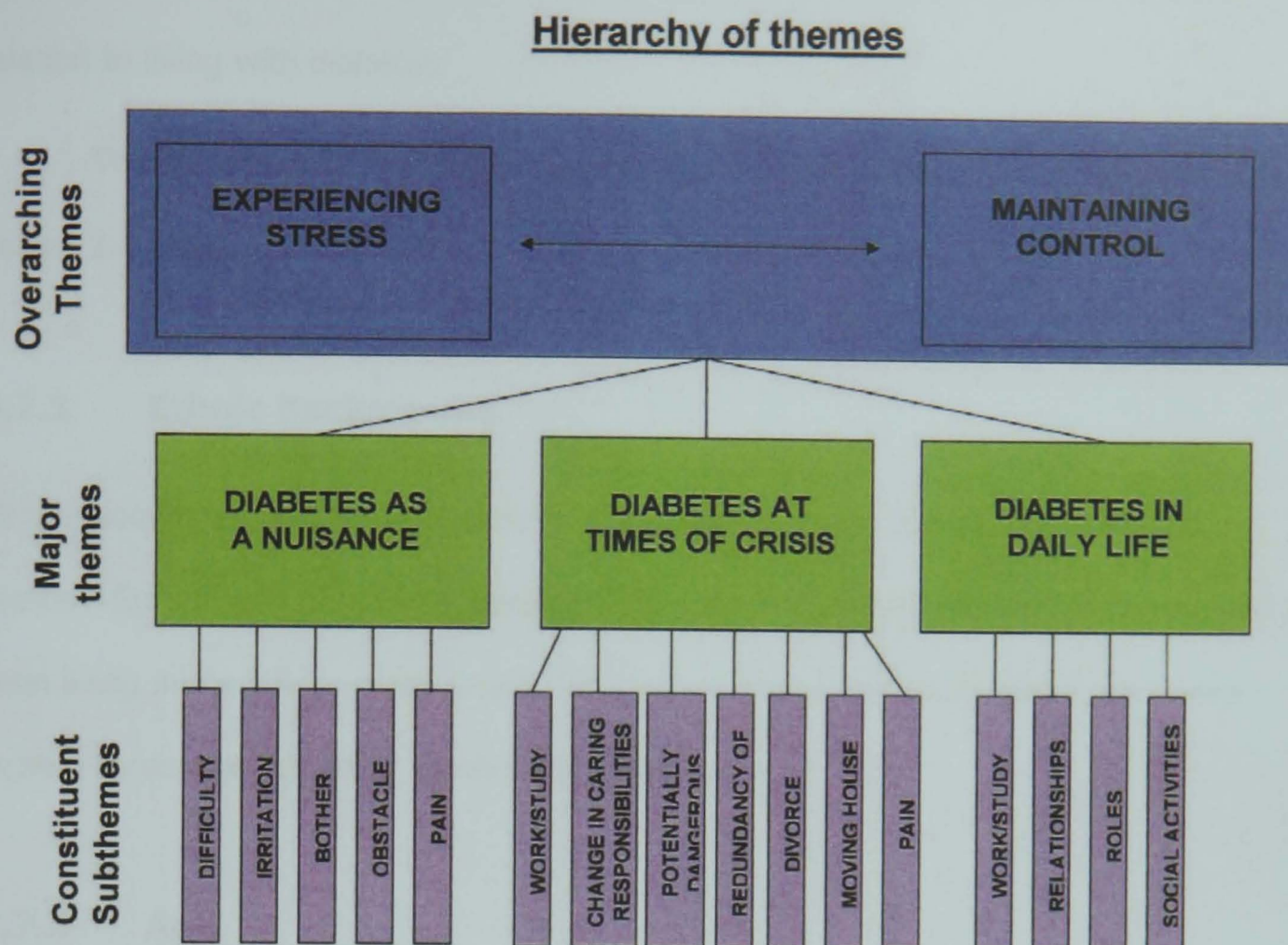


Figure 3.2 *Hierarchy of themes.*

3.7 The research participants

However, before introducing the results of the data analysis, it is central to the thesis to introduce the women who provided the data for analysis. All women interviewed have been given pseudonyms in order to protect their identities in keeping with the ethical aims of the study. Some of the women stated that they would be happy for their names and even their photographs to be included in these chapters, however this assumption could not be made for all of the women in the study, and at least one woman wished to keep the fact that she had taken part in the study hidden from her husband. Their characteristics have been included in the main body of the study in order to make them visible, and not 'hidden' in an appendix in order to make them visible. Their individual and collective profiles are concerned with the social context within which the 23 women

interviewed lived, to 'set the scene' prior to examining their experiences of stress in relation to living with diabetes.

The social and diabetes profiles of the 23 women interviewed are presented in Tables 3.4 and 3.5.

3.7.1 Ethnic background

All the women were of white Caucasian extraction, 21 were British, plus one from Western Europe and one North American. All were from similar Western cultures, and had been living in the UK for many years. All lived within the United Kingdom, and were located throughout England, Scotland and Wales.

3.7.2 Age

All women were aged between 41 and 60 years. Eleven were aged between 41 and 50, and 12 between 51 and 60. The mean age was 49.8 years. Women were defined as being in the younger age range if they were aged between 41–50, and in the older age range if they were aged between 51–60.

3.7.3 Work

Eighteen of the women (78%) of the women interviewed worked in a paid capacity. A slight majority worked part time (10/18), with the remaining 8 working full time.

Slightly more of the women who worked part time were in the older age range (6/10), with only 3/8 of those working full time being aged between 51 and 60. In the younger age range, there was little difference in the numbers of those working full (5/9) and part time (4/9). More than half (10/18) the women interviewed worked in a professional capacity, with 7 out of the remaining 8 working in administration, and one woman as a school meals supervisor.

Table 3.4 – Social profile of the 23 women interviewed

Name	Age Band	Work	Caring for family members other than children living at home	Caring for children at home	Children left home	Household members
Carol	51-60	Part time Administrative	Mother in law	No	Yes	Partner
Lesley	41-50	Full time Administrative	No	Yes	No	Partner Children
Josie	41-50	Full time Administrative	No	No	No	Partner
Lois	41-50	Full time Professional	Mother	Yes	No	Partner Children
Gina	51-60	Full time Professional	Daughter	No	Yes	Father
Joy	51-60	No	Granddaughter	No	Yes	Partner
Pam	51-60	Full time Administrative	No	No	Yes	Partner
Carla	51-60	Part time Professional	Estranged Partner	Yes	No	Estranged partner Children
Angela	51-60	No	No	No	No	None
Lynn	41-50	No	No	No	No	Partner
Irene	51-60	Part time Professional	No	No	Yes	Partner Student
Jane	41-50	No	Daughter	No	Yes	Partner
Tanya	41-50	Full time Professional	No	Yes	No	Partner Children
Claire	51-60	Full time Professional	Mother	No	Yes	Partner
Judith	41-50	Full time Administrative	Parents	Yes	No	Child
Paula	41-50	Part time Auxiliary role	No	No	Yes	Partner
Joanne	41-50	Part time Administrative	No	Yes	No	Partner Children
Joan	51-60	Part time Professional	No	No	Yes	Partner
Janice	41-50	Part time Professional	Mother	Yes	No	Partner Children
Marge	51-60	Part time Professional	No	No	No	Partner
Carmen	51-60	Part time Professional	No	No	Yes	Partner
Mandy	51-60	No	Mother	Yes	No	Child
Annette	41-50	Part time Administrative	No	Yes	No	Partner Children

Table 3.5 – Diabetes profile of the 23 women interviewed

Name	Age Band	Duration of diabetes in years since diagnosis	Duration of insulin treatment in years	Family members with diabetes
Carol	51-60	47	47	None
Lesley	41-50	20	20	None
Josie	41-50	20	20	None
Lois	41-50	14	14	None
Gina	51-60	41	41	None
Joy	51-60	20	5	Husband and siblings
Pam	51-60	10	3	Sister
Carla	51-60	11	7	None
Angela	51-60	9	6	None
Lynn	41-50	6	1	Parents
Irene	51-60	47	47	Father
Jane	41-50	26	26	Niece
Tanya	41-50	3	3	None
Claire	51-60	5	5	None
Judith	41-50	17	16	None
Paula	41-50	20	20	Father
Joanne	41-50	38	38	None
Joan	51-60	39	39	None
Janice	41-50	25	25	None
Marge	51-60	46	46	Father/brother /nephew
Carmen	51-60	20	20	None
Mandy	51-60	20	20	Mother
Annette	41-50	36	36	Grandmother

3.7.4 Caring

Ten women reported having a caring role for other members of their family. None of these family members lived with the women, with one exception, Carla, whose estranged husband lived in a separate part of the house. This had the implication of the women having additional caring responsibilities outside the home, mainly for elderly relatives. Joy was the exception to this, who cared for her granddaughter within her home, but who did not live there permanently. Seven out of the ten women were also in paid employment, and four of these also had children living at home, demonstrating the multiple roles they held.

3.7.5 Family structure

Without exception, the women described being a family member and the relationships within the family as being the most important in their lives. The composition of the family unit meant that in some cases, the roles of being a partner and mother had been, or still was, carried out simultaneously. Of those nineteen women who had children, nine still had children living at home, and ten had children who had left home. Six women whose children still lived at home lived with their partner, with the other three being single parents. Nine of those whose children had left home still lived with their partner, with the exception of Gina who lived with her father. Three of the four remaining women lived with a partner, and one woman lived alone. The structure of the family unit had implications for the roles the women were responsible for, and also for the amount of support given and received, as will be discussed in the following data chapters.

3.7.6 Duration of diabetes experience

Within the age group of the women selected for interview, there was variation in the amount of time they had had diabetes, ranging from 3–47 years (mean duration 23.5 years), indicating that the experience of living with diabetes ranged from those diagnosed

during childhood, to those diagnosed in midlife. For those women who had been diagnosed in childhood/early adulthood, it is reasonable to assume that they had Type 1 diabetes. However, the picture is less clear for those diagnosed later in life, as they may have had either Type 1 or Type 2 diabetes. However, for the purpose of this study this is not relevant, as it is the treatment of the condition with insulin and the associated outcomes that are of interest.

3.7.7 Duration of insulin treated diabetes

Seventeen of the women had been treated with insulin since diagnosis, but the remaining six had been treated with diet and tablets prior to commencing insulin for varying amounts of time (mean duration 22 years). For Judith this had been for less than a year, whereas Joy had been on insulin for 5 years, despite having been diagnosed for 20. Tanya was the most recently diagnosed as she had had diabetes for 3 years, and had been treated with insulin for the whole of that time, and Lynn had been treated with insulin for the least amount of time (1 year), although diagnosed for 6, suggesting that for some women the experience of managing insulin treated diabetes was only a part of their total experience of living with diabetes.

3.7.8 Family members with diabetes

During the time that the women had had diabetes, nine had had contact with other family members with diabetes. Pam had a sister with diabetes. Joy had twelve siblings, of which at least five were affected. She also diagnosed her husband from the symptoms he was exhibiting. Jane had a young niece who had recently been diagnosed with diabetes. Mandy, Lynn, Irene and Paula had parents with diabetes. Paula's father had recently died from cancer, although he had previously been diagnosed with diabetes. Annette's grandmother had Type 2 diabetes, which she had developed in later life. Several members of Marge's family also had diabetes, including her father, nephew and brother.

Chapter 4 will commence with individual holistic cameos of each woman.

CHAPTER 4

Diabetes as a nuisance

This first data analysis chapter illustrates the major theme identified from interpretative phenomenological analysis (IPA) of the interview data – '*Diabetes as a Nuisance*'. This theme is also the title of the thesis and is taken from a direct quotation from the words of one of the research participants.

4.1 The women themselves

The initial section is concerned with a holistic representation of each woman. Their profiles have been presented in a tabular form in Section 4.1 in the previous chapter. They have been presented in a less fragmented and more discursive manner here, in keeping with the feminist and IPA approaches which focus upon the individual experience.

Carol was in her fifties and lived in a village location with her husband, and had one child in her twenties who did not live with them. She worked part time in an administrative capacity. She had a caring role for an elderly parent who did not live with them. She had been diagnosed with diabetes and treated with insulin for 47 years. She had a great aunt who had had diabetes.

Lesley was in her forties and lived in a village location with her partner and two children of primary school age. She worked full time in an administrative capacity. She had no other caring responsibilities. She had been diagnosed with diabetes and treated with insulin for 20 years. No other family members had diabetes.

Josie was in her forties and lived in a new town with her husband. She worked full time in an administrative capacity. She had no children and no other caring responsibilities. She had been diagnosed with diabetes and treated with insulin for 20 years. No other family members had diabetes.

Lois was in her forties and lived in a suburb of a large city with her husband and two teenage children. She worked full time in a professional capacity. She cared for her mother who lived nearby. She had been diagnosed with diabetes and treated with insulin for 14 years. No other family members had diabetes. Sadly, Lois died in an accident during the period of the research study.

Gina was in her fifties and lived in a suburb of a large city with her father. She had one child in her twenties who did not live with her. She worked full time in a professional capacity. She had no other caring responsibilities. She had been diagnosed with diabetes and treated with insulin for 41 years. No other family members had diabetes.

Joy was in her fifties and lived in a new town with her husband. She had five children in their thirties who did not live with her. She did not work in a paid capacity. She had a caring role for her grandchild of primary school age who did not live with her. She had been diagnosed with diabetes for 20 years and had been treated with insulin for 5 years. Her husband and several siblings also had diabetes.

Pam was in her fifties and lived in a new town with her husband. She had three children in their thirties who did not live with her. She worked full time in an administrative capacity. She had no other caring responsibilities. She had been diagnosed with diabetes for 10 years and had been treated with insulin for 3 years. No other family members had diabetes. She had recently been undergoing radical treatment for breast cancer at the time of the interview.

Carla was in her fifties and lived in a village location with her three teenage sons. She worked part time in a professional capacity. She had a caring role for her estranged

husband who lived in a separate part of the house. She had been diagnosed with diabetes for 11 years and had been treated with insulin for 7 years. No other family members had diabetes.

Angela was in her fifties and lived alone in a village location. She did not work in a paid capacity, but undertook voluntary work. She had no children and no other caring responsibilities. She had been diagnosed with diabetes for 9 years and had been treated with insulin for 6 years. No other family members had diabetes. She also suffered from rheumatoid arthritis which caused her pain and limited her mobility.

Lynn was in her forties and lived on the outskirts of a large city with her husband. She did not work in a paid capacity. She had no children and no other caring responsibilities. She had been diagnosed with diabetes for 6 years and had been treated with insulin for 1 year. Both of her parents had diabetes. She also suffered from psoriasis and arthritis, both of which caused her pain and discomfort.

Irene was in her fifties and lived on the outskirts of a large city with her husband and lodger. She had two children in their twenties who did not live with her. She worked part time in a professional capacity. She had no caring responsibilities since her mother had died a year prior to the interview. She had been diagnosed with diabetes and treated with insulin for 47 years. Her father and great aunt had both had diabetes.

Jane was in her forties and lived in a small industrial town with her husband. She had three children in their twenties who did not live with her. She did not work in a paid capacity and had no other caring responsibilities. She had been diagnosed with diabetes and treated with insulin for 26 years. Her niece also had diabetes.

Tanya was in her forties and lived in a village with her husband and two teenage children. She worked full time in a professional capacity. She had no other caring responsibilities. She had been diagnosed with diabetes and treated with insulin for 3 years. No other family members had diabetes.

Claire was in her fifties and lived with her husband on the outskirts of a large city. She had two children in their twenties who did not live with her. She worked full time in a professional capacity. She cared for her mother who lived in residential care nearby. She had been diagnosed with diabetes and treated with insulin for 5 years. No other family members had diabetes.

Judith was in her fifties and lived in a new town with her teenage daughter. She worked full time in an administrative capacity. She had a caring role for her parents who lived nearby. She had been diagnosed with diabetes for 17 years and had been treated with insulin for 16 years. No other family members had diabetes.

Paula was in her forties and lived on the outskirts of a large city with her husband and teenage daughter. She also had one son at university. She worked part time in an auxiliary school within a school. She had no other caring responsibilities. She had been diagnosed with diabetes and treated with insulin for 20 years. Her father had had diabetes.

Joanne was in her forties and lived on the outskirts of a large city with her husband and two teenage children. She worked part time in an administrative capacity. She had no other caring responsibilities. She had been diagnosed with diabetes and treated with insulin for 38 years. No other family members had diabetes.

Joan was in her fifties and lived in a large city with her husband. She also had a child in her thirties who did not live with her. She occasionally worked part time in a paid capacity in a professional role. She had no other caring responsibilities. She had been diagnosed with diabetes and treated with insulin for 39 years. No other family members had diabetes.

Janice was in her forties and lived in a large city with her husband and two children in their twenties. She worked part time in a professional role from home. She had

a caring role for her mother who lived nearby. She had been diagnosed with diabetes and treated with insulin for 25 years. No other family members had diabetes.

Marge was in her fifties and lived in a village with her husband. She worked part time in a professional capacity from home and also was engaged in voluntary work. She did not have children and had no other caring responsibilities. She had been diagnosed with diabetes and treated with insulin for 46 years. Her father, brother and nephew also had diabetes.

Carmen was in her fifties and lived in a small town with her husband. She had two children in their thirties who did not live with her. She worked part time in a professional capacity. She had no other caring responsibilities. She had been diagnosed with diabetes and treated with insulin for 20 years. No other family members had diabetes.

Mandy was in her fifties and lived in a village with her teenage son. She did not work in a paid capacity. She had a caring responsibility for her mother who lived nearby and who also had diabetes. She had been diagnosed with diabetes and treated with insulin for 20 years.

Annette was in her forties and lived in a remote rural location with her husband and two teenage children. She had also had another child, who had died some years previously. She worked part time in an administrative capacity from home. She had no other caring responsibilities. She had been diagnosed with diabetes and treated with insulin for 36 years. No other family members had diabetes.

The remainder of this chapter is divided into two sections – an exploration of the subthemes that constitute the major theme of diabetes as a nuisance, followed by a poetic representation of diabetes as a nuisance.

The next section provides an IPA thematic analysis of the interview data, illustrating '*diabetes as a nuisance*' as a major theme emerging from the interview data.

4.2 IPA thematic analysis

Figure 4.1 illustrates the constituent subthemes which were a part of the major theme of diabetes as a nuisance, and with the major theme itself.

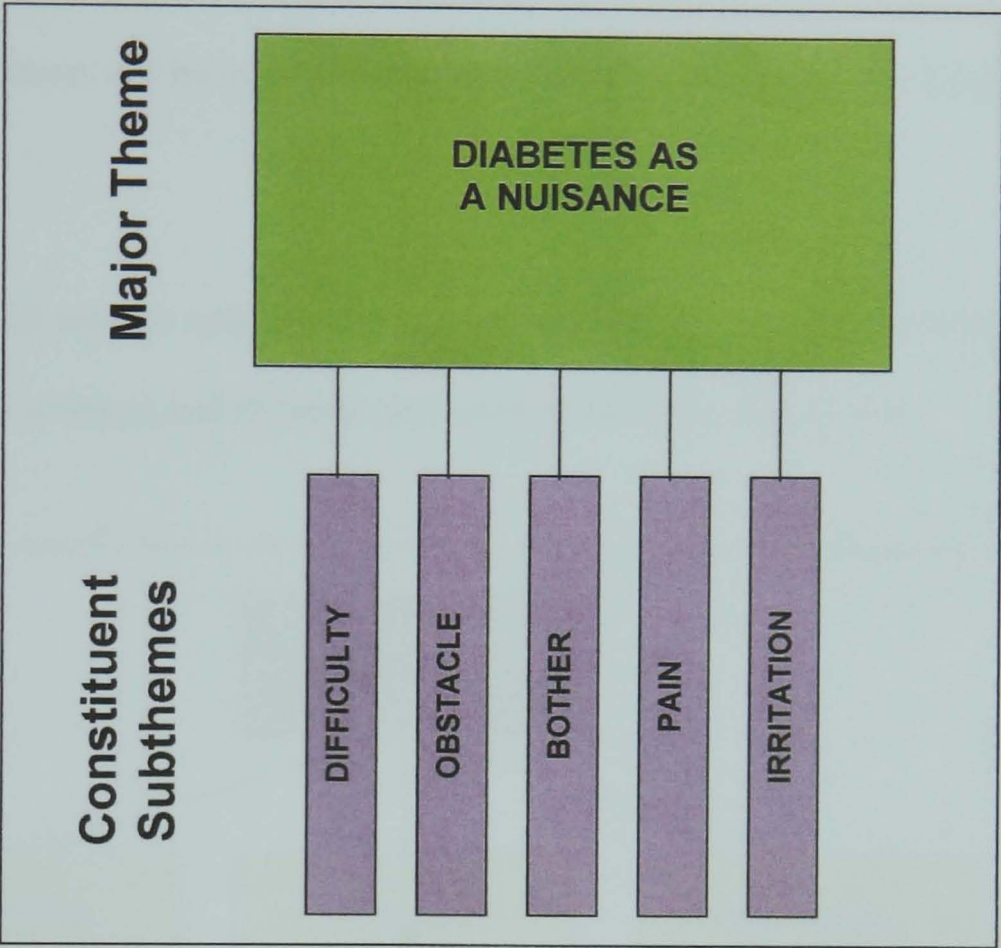


Figure 4.1 Major theme of nuisance and its constituent subthemes.

4.2.1 Constituent themes of the major theme of nuisance

Although some women directly used the word '*nuisance*' in their accounts there were other words and descriptions used which were part of, and associated with, the concept of nuisance. Figure 4.1 illustrates that each of the 5 constituent subthemes are part of the overall major theme of nuisance.

The subthemes are that diabetes is a:

- Difficulty
- Obstacle

- Bother
- Pain
- Irritation

Each of these themes will be considered in the following sections of this chapter.

Difficulty

Eighteen of the 23 women interviewed referred to difficulties associated with diabetes, on a a) practical, b) physical and c) emotional level as shown in Figure 4.2.

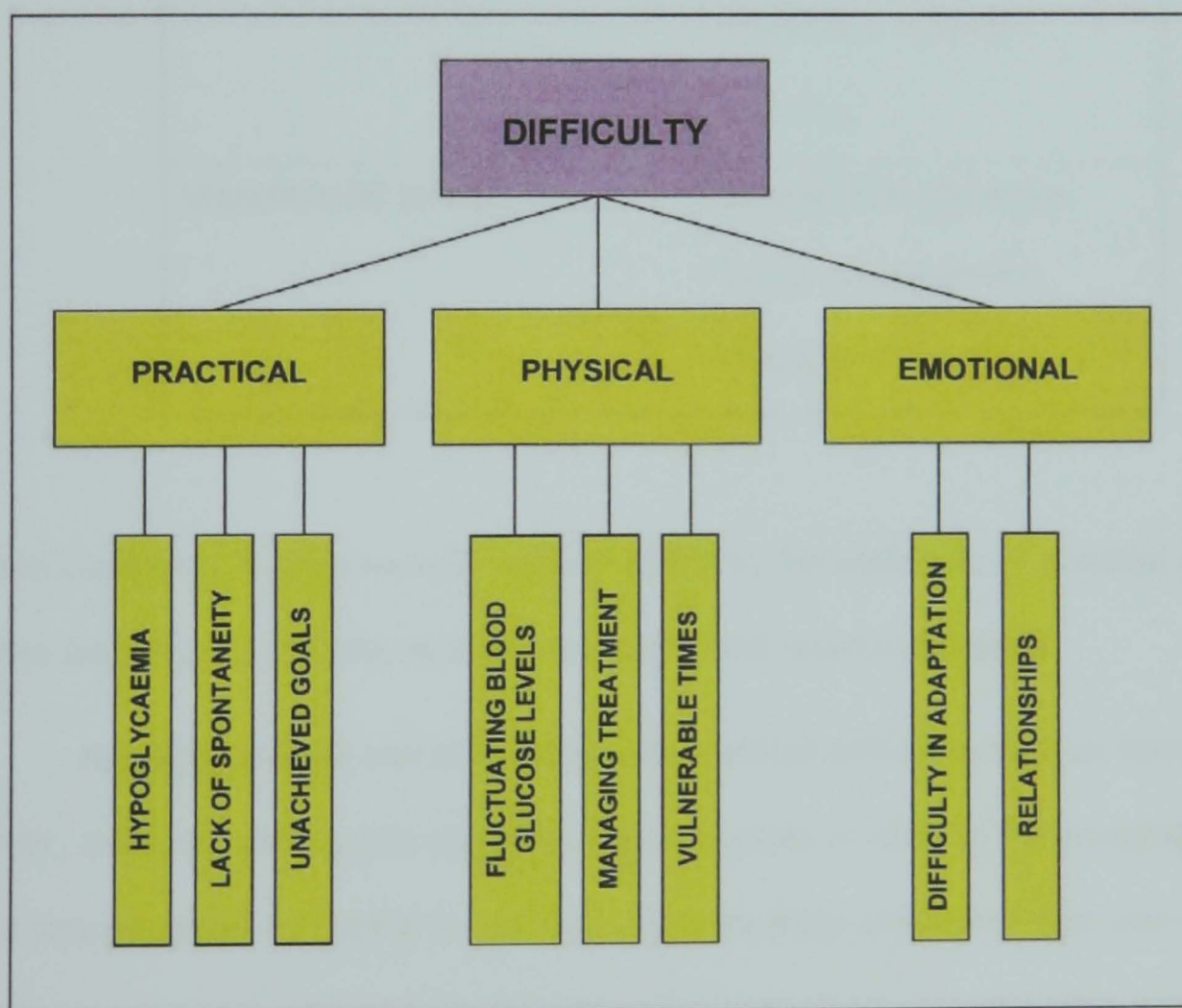


Figure 4.2 Constitution of subtheme of difficulty.

a) **Practical Difficulties**

Clustered themes which comprised the subtheme of practical difficulties are shown in Table 4.1.

Table 4.1 Clustered themes comprising the subtheme of practical difficulties

Hypoglycaemia	Managing career Childcare Driving Shopping
Lack of spontaneity	Rigidity of eating regimes Treatment regimes Planning
Unachieved goals	Biographical disruption Career management Financial instability

Three clusters of themes were identified relating to the subtheme of practical difficulties. These were hypoglycaemia, lack of spontaneity and unachieved goals.

Hypoglycaemia was associated with practical difficulties such as managing a career, childcare, driving and shopping. This was often in relation to managing a lifestyle that was perceived as normal by the women themselves and others, and was concerned with assessing and managing the risk associated with short and long term outcomes of living with diabetes. Jane found it difficult to manage her career due to hypoglycaemic attacks, and subsequently resigned from something she had wanted to do for many years. Lesley had the opportunity to do a glamorous job, but declined because of the potential difficulties.

In terms of childcare Judith, like Carla, developed diabetes following the birth of her child. Judith found the practicalities of coping with a baby and a long term condition difficult to deal with. Paula also initially had gestational diabetes, that became Type 1 diabetes, and she had to deal with avoiding hypoglycaemia whilst driving the children.

When I used to have to take the kids to school and I used to have to drive them I always had to make sure that I'd eaten before I drove and it was a bit difficult. As I say I would have liked to have gone back to full time work by now, but I don't think that's really feasible.

(Interview data Paula 96–100)

Annette felt unable to drive because of the risk of hypoglycaemia and found this difficult as she lived in such a remote area and was dependent upon public transport or other people to take her shopping.

Lack of spontaneity was described in relation to perceptions of the need for planning and rigidity, particularly associated with eating and treatment regimes. Jane reported difficulties in having to eat at certain times, Marge with following a set routine in terms of monitoring and testing. Carol found it difficult to arrange mutually acceptable mealtimes for her and her husband. Annette found the difficulties associated with diabetes a constant presence, but acknowledged that she was not alone in this. Her husband also managed a long term condition, and she acknowledged this as a positive thing, as he had an understanding, particularly when her diabetes impacted upon him, such as when she was hypoglycaemic, and as a result there was more equality within their relationship.

Because of going through I suppose a daily difficulty of living with diabetes I hope that I can appreciate that I'm not the only one and other people have to do that as well. From that point of view I think I can see it as a plus point, because it's extended my understanding. I think also from a plus point, but with negative undertones, it can make my family life stressful, but we laugh about it, and I also

think....My partner has a (long term condition), so I'm very fortunate, this does seem a perverse thing to say, but I'm very fortunate in that he also has a problem, so we can't sort of hurl at each other 'well, you're the cripple, or you're the cripple', because we both have a medical problem, and I think perhaps that helps in some respect.

(Interview data Annette 117–131)

Various aspects of daily diabetes management posed difficulties for the women interviewed. In the main, these were related to a desire to maintain a perceived 'normal' lifestyle, but having to succumb to the requirements of managing diabetes, to avoid the consequences described above, in both the long and short term. These included the giving of injections and carrying insulin pens; lack of appetite but still being required to eat and inappropriate insulin adjustment; timing of meals being inconvenient for the diabetes regimen, either having to stick to a routine, or patterns of eating being erratic. Joanne referred to the problem of keeping blood glucose levels within the accepted normal limits of between 4 and 7 mmols per litre, and avoiding hypoglycaemia (below 4 mmols per litre). However, on a positive note Jane acknowledged that due to technological advances, some of the problems relating to daily management were much less today.

Now it's a lot easier than it was when I was first diagnosed, I used to have to boil the syringes, and there was no easy blood glucose testing machines, it was all test tubes and drops of urine and that, which was a bigger problem I think really, things are a lot easier now.

(Interview data Jane 292–296)

Unachieved goals related to expected outcomes, particularly in relation to career and financial aspirations, which were also related to the theme of hypoglycaemia as previously described in this section. Paula had experienced financial hardship as she had felt unable to continue with her job on a full time basis, and had taken a drop-in pay when she

changed to part time hours. This had happened at a time of financial pressure on the family as their children started university.

b) ***Physical difficulties***

Clustered themes which comprised the subtheme of physical difficulties are shown in Table 4.2.

**Table 4.2 Clustered themes comprising the
subtheme of physical difficulties**

Fluctuating blood glucose levels	Hypoglycaemia	Punishment Embarrassment Alcohol Warning signs
	Hyperglycaemia	Concentration Tiredness
Managing aspects of treatment	Injections Remembering to take medication Fitting in exercise Weight gain	
Vulnerable times	Pregnancy Times of crisis	

Three clusters of themes were identified relating to the subtheme of physical difficulties. These were fluctuating blood glucose levels, managing treatment and vulnerable times.

Fluctuating blood glucose levels caused difficulties not only for the women in the study themselves, but also for the people with whom they had relationships. Hypoglycaemia resulted in physical and emotional difficulties for Carol as a child when she would be sent to her room as a result of her behaviour when her blood glucose levels

were low as a punishment. As an adult she found hypoglycaemia posed social problems if she needed to eat in an atmosphere that was quiet such as unwrapping sweets in a cinema or theatre which she found embarrassing. Lois reported that taking alcohol in moderation could induce hypoglycaemia for her, which could be problematic the following day in terms of her cognitive functioning. Lynn, Lois, Janice and Annette reported loss of warning signs of hypoglycaemia, and Irene reported it '*creeping up*' on her, as did Joanne when she was out on a day trip with a group of people and wanted to avoid being disruptive. Joanne commented that she would find it impossible to avoid hypos without blood glucose monitoring being available due to her losing the warning signs of a potential hypoglycaemic attack.

Tanya found concentrating difficult when her blood glucose levels were high; whereas Lynn was so busy concentrating at studying that she forgot to eat on occasions and became hypoglycaemic, and found it difficult to regain this concentration after the intrusion of the diabetes.

Sometimes when my blood sugar's high, say after lunch or something if it's a bit higher than it should be , I find it difficult to concentrate, I really have to make myself focus, and that is the diabetes that's doing that.

(Interview data Tanya 608–612)

Managing aspects of treatment caused physical difficulties for some of the women. Both Carol and Paula found injecting insulin to be a difficulty for them initially, and Janice frequently forgot to take her oral hypoglycaemic tablet therapy, with the result that her blood glucose levels became high and she felt unwell. Carol also found it difficult to fit in exercise on a regular basis and did not like feeling constrained to a habitual way of life, and shared a common difficulty with Lynn of not being able to successfully lose weight.

Vulnerable times were associated with certain episodes in life being identified where these physical difficulties had a greater impact, such as during pregnancy and immediately following delivery, during major life events such as a husband’s redundancy which Lois described as a ‘*hidden factor*’ (Interview data Lois 604). Although she was controlling the majority of aspects of living with diabetes, stress was the one thing over which she perceived that she had no control, and which was affecting her blood glucose level adversely.

(Stress) raised my blood sugars. It made them much more difficult to control because you were thinking you were controlling it because your diet was under control but yet your blood sugars weren’t responding to the insulin or the diet so there was this hidden factor that you couldn’t control.

(Interview data Lois 600–604)

c) **Emotional difficulties**

Clustered themes which comprised the subtheme of emotional difficulties are shown in Table 4.3.

Table 4.3 Clustered themes comprising the subtheme of emotional difficulties

Difficulty in adaptation	Disruption due to hypoglycaemia Embarrassment – work Fainting Worry/fear Uncertainty
Relationships	Ownership and input from others Concern for others Health care professionals Change of role in family

Two clusters of themes were identified relating to the subtheme of physical difficulties.

These were difficulty in adaptation and relationships.

Difficulty in adaptation is concerned with a variety of emotional difficulties in relation to living with diabetes, with worry and fear about the disruption associated with becoming hypoglycaemic being common to many of the women. Carol and Janice described feeling embarrassed if they became hypoglycaemic, particularly in the work situation. Lynn referred to being concerned about the additional difficulties hypoglycaemia could cause for other people. For Tanya it was the difficulty of coming to terms with the fact that she may become unconscious that was the issue, as she was afraid of fainting. This was similar to Claire's difficulties in dealing with the potential for hypoglycaemia to occur unexpectedly at any time, and disrupt her planned activities.

In order to avoid hypoglycaemia the women perceived that a high degree of self-care was necessary, which had the potential to impose upon their lives. However, if they did not engage in this self-care behaviour, there was the potential for hypoglycaemia to intrude, with its unwanted effects.

Some of the women identified uncertainty and loss of spontaneity as difficulties, together with the ambiguity of the cause of any difficulties. Pam could not decide whether her difficulties were due to age, weight or diabetes and Tanya found it difficult to identify the cause and effect of complications. Angela and Lynn both had an arthritic disease as well as diabetes, and they found difficulty in separating the two. Irene and Janice found the need to plan and the lack of spontaneity a difficulty, and found it difficult to relax as diabetes was always at the back of their minds. Irene described herself as

Not being able to be entirely relaxed, just having to think all the time and being responsible ... it has affected the rest of my personality. I'm sure that's true and not being able to relax as much and having to plan all the time.

(Interview data Irene 160–1061 and 2570–2573)

Relationships were referred to specifically in relation to partners and family members and Annette referred to her perceived change of role within the family unit. She reported finding it very difficult to cope with the effect that her diabetes had on her husband and children.

To my mind, it's as if I've lost control of it, and the control has now passed to my husband and my children after him, and to me it feels rather like offloading my responsibility onto them, which I find difficult to cope with, which I think also reflects on what happened last night. I find it very difficult to cope with the fact that I should have to have a disturbed night's sleep because I wasn't well and he looked after me. I think it should be my stress and my problem and I feel as if that's been taken out of my hands and I find that very difficult to cope with.

(Interview data Annette 1543–1556)

Other women reported emotional challenges within the family arena, also often linked with relationships with others. Tanya's husband would not talk to her about her diabetes, and preferred her to manage it independently, which she found difficult at first; whereas in contrast Marge felt that her husband had a tendency to take over, which she found equally as difficult to deal with.

My husband gets into a bit of a tiz over all this (diabetes) and he starts trying to organize it all, so I just opt out, and I just leave him to do it, and the whole thing falls apart, so I think 'oh, I must remember not to do that again.

(Interview data Marge 163–167)

Obstacle

It can be seen from Figure 4.3 that the theme of obstacle has two constituent themes of problem and hassle. These will each be discussed in turn below. Both of these in effect refer to obstacles to be overcome in daily life. Obstacles are conceptually distinct from difficulties as they are not integral to the management of diabetes itself but were

presented to the women in the course of them attempting to obtain care for their diabetes within the health care system. It was the processes and procedures associated with this system which proved problematic to the women, rather than diabetes or its management by the women.

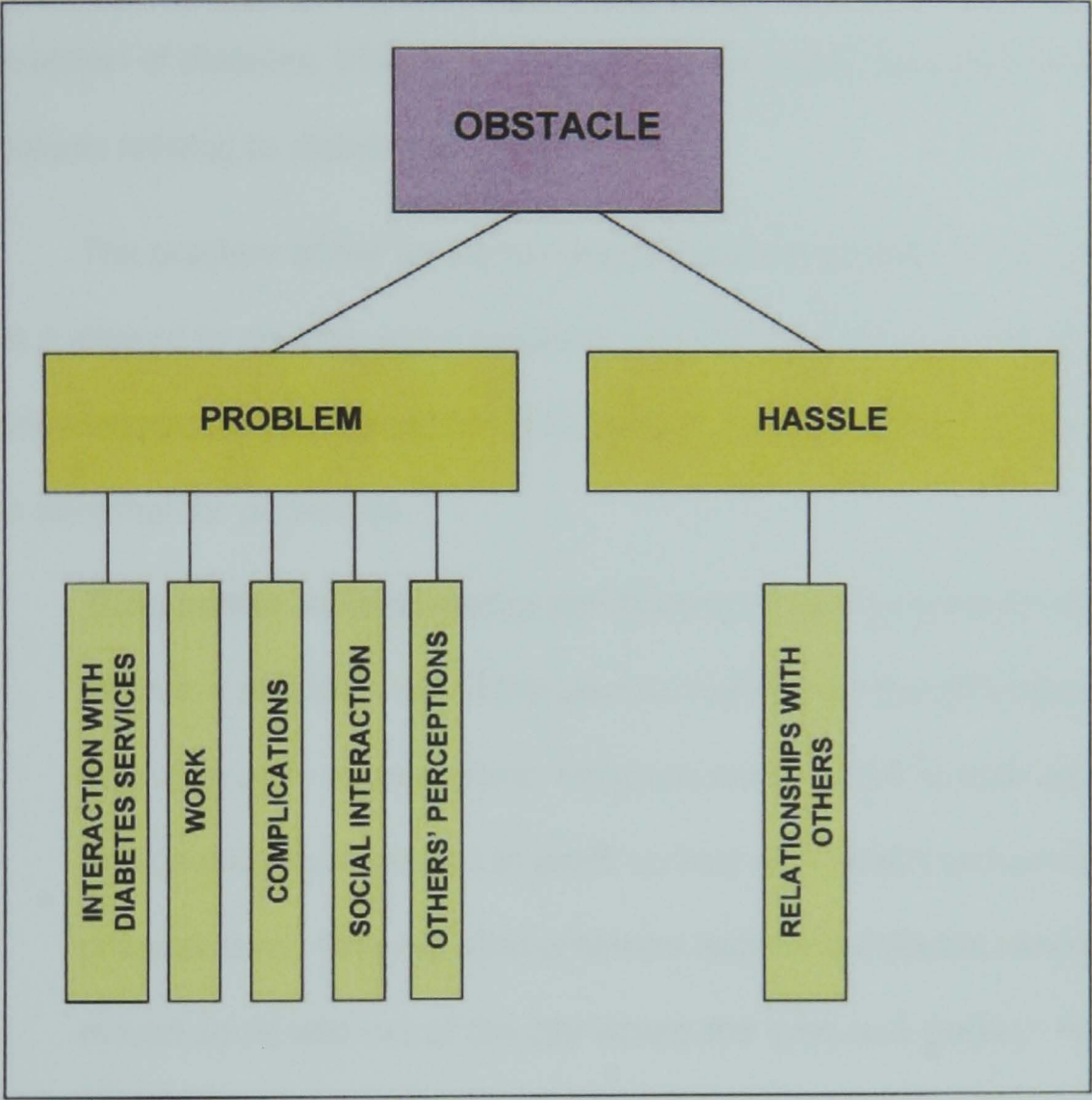


Figure 4.3 Constitution of subtheme of obstacle.

Problem

All of the women with the exception of Carla and Carmen used the word '*problem*' in relation to their diabetes, and referred to conceptualisation of various issues as a problem and/or a practical obstacle which required resolution.

At all times, the women lived within a social context, requiring relationships between themselves and a variety of other people. These relationships occurred in a range of settings – work, home, social situations and medical settings in the hospital or community. The problems described centred upon: a) interactions with diabetes services, b) work, c) long and short term complications, d) social interactions and e) other peoples' perception of diabetes. Integral to all of the above was a sense of ownership of the problems relating to diabetes.

The gradient of the problems ranged from being minor to the acknowledgement that if allowed to develop some problems may have a fatal outcome. There was an acknowledgement of the need for ownership of diabetes related problems and that there was potential for prevention.

- a) ***Interaction with diabetes services*** were seen as problematic by a number of women – problems with other people, rather than the difficulties of coping with their own self - management. Problems were related to both accessing services and developing strategies to avoid contact with health care professionals. On a practical level, Gina reported problems accessing diabetes services, as they had moved some way out of the city where she lived and worked. Marge had found problems with obtaining results of blood tests from a practice nurse, and eventually cancelled appointments at the diabetes clinic.

For Carol, hospitalisation was highly problematic. One of the problems for her was getting acknowledgement that her experience was valid and a confrontation developed, leading to her having problems developing trust with health care professionals.

Being held down and being given an injection against your will is not my idea of anything I ever ... it was torture it really was and again that was a problem and has meant problems building any kind of trust that I might have had for the medical profession. I mean, how could they do that?

(Interview data Carol 2257–2262)

This was also the experience of Angela in relation to receiving what she believed to be an appropriate insulin dose during her hospital stay. Marge had problems obtaining an adequate supply of needles on prescription. During the early stages of having diabetes, Lois had difficulty in getting a diagnosis from her then GP and felt that education at that time was inadequate. When she was referred to a diabetes clinic, it was getting access to health care professionals due to the outpatient appointment system, and overcrowding in the outpatient clinic that was problematic, rather than the professionals themselves. Ironically, it was the wait in the outpatient clinic that led to hypoglycaemia. Irene found lack of continuity of staff in the clinic problematic, as did Joy with her interaction with health care professionals and Judith with the lack of time allocated to her. Judith graphically describes the problems with the diabetes clinic illuminating her frustration and eventual withdrawal from the situation, which mirrors the experience and views of other women.

It's impossible. I mean you only see the doctor for 2 minutes. You have to queue up to be weighed, queue up to have your wee tested, queue up to have a blood test, and all these different queues, you find yourself at the end of a line all the time. It's not very organised. They pack far too many people on to the time allowed, and then you normally get some big nurse, you get on the scales, 'oh we've put on since last time'. I think 'I'm going to sock you in a minute', or else 'you've lost weight, what have you been up to?', and it's always the one with the really loud voice and it goes right down the corridor. It's not very confidential, that I've got any secrets, I haven't, but it's a bit kind of embarrassing, and there's also a lot of old people who tend to take their time. And it's not that I don't like old people, I love old people but, you know, you think 'come on, in and out,' I don't want to wait three quarters of an hour for Mrs so and so to take her shoes off to

get on the scales and moan about her walking stick, and she needs a wee, you know, 'please just get me in and out of here'. You know I sit there reading a book, and then I get fed up and wander off 'I don't need this'.

(Interview data Judith 513–535)

Relationships with health care professionals were not without their problems, and Carol in particular had experienced several negative incidents, which she described as making it problematic for her to not be defensive in consultations. Below she refers to being pressurised to give her own insulin when first diagnosed during childhood, and her feelings of powerlessness associated with this.

They tried to get me to do it to myself and I can still remember the nurse finally, I mean not being able to do it. It's that simple I just did not want to stick a needle in my leg. I'd had lots of needles by that point and I knew that it wasn't going to kill me , but I just found it really, really difficult ... my memory of it is that I just completely went blank when the nurse took my hand and pushed it in my leg. I was holding this syringe but I can't say that I gave myself that injection, and I really did just space out for a while and couldn't stop shaking afterward. It was really, really difficult for me to do that.

(Interview data Carol 730–735 and 740–747)

Not being treated as an individual was a problem for Annette and Lesley, although Lesley acknowledged the problems for health care professionals as well as women with diabetes. Gina also identified with the problem of everyone's diabetes being their own personal condition requiring a degree of autonomy in its management. Diabetes was a condition that was theirs alone and affected their own body, owned by themselves and making each person with diabetes unique, rather than a common experience shared by everyone with diabetes. She refers to her own trajectory with diabetes, and compares it to that of others, recognising that there were differences.

I've been quite good and lucky, I know other people who aren't, but it's a very personal thing, each person's different ... I think we do know our own diabetes better than anybody else and how we feel, because it's not a general illness, well it's not an illness, it's not a general condition, that's the same for everybody.

(Interview data Gina 478-480 and 1366-1370)

- b) Carol, Lois, Joy, Jane and Paula all reported problems in the *work* situation in relation to their diabetes. Carol had divulged her diabetes as she was having hypoglycaemic attacks without warning, and experienced a negative change in attitude towards her from a senior colleague. Lois found that work itself began to affect her diabetes at the end of the day when she was tired and stressed and needed to be addressing her family roles when she returned home. Joy had difficulty with colleagues not understanding her need to eat at a certain time and this had a negative effect upon their relationship and also put her at risk of developing hypoglycaemia. Jane found the irregularity of her hours problematic in terms of timing her meals and Paula suffered hypoglycaemia at work, and had to rely on colleagues noticing as she was unaware and taking over responsibility for her wellbeing.

It's more of a problem when I'm in the playground, but then they know I've usually got biscuits in my pocket and if they think I look as if I'm not really noticing what's going on they'll say to me 'go in and eat that biscuit'.

(Interview data Paula 1142-1146)

Claire was adamant that she should not be seen as the person with a problem at work, and found this the biggest problem in a professional sense, as she reported that she did not feel in control of the situation.

- c) Many of the problems associated with the *long and short term complications* of diabetes have been discussed in the above section. In addition, Carol described constant problems with thrush and cystitis, and went on to say that she would

contemplate suicide if she was to develop retinal eye disease, whereas Marge had already developed cataracts which had been successfully treated. She was however concerned that there was a family history of diabetes and her father had developed cerebral vascular problems and had a stroke. Lois described her problems with cold sores and the problems she experienced in terms of the length of time they took to heal, and how her blood glucose levels were unpredictable in hot weather. Joy was concerned about developing complications with her feet and Joan had skin problems. Pam acknowledged the seriousness of the potential development of complications and expressed a desire that she did not develop them, whilst Lesley and Janice were concerned with their weight.

- d) Other areas described as problematic were *social interactions* and in particular events generally related to food, and the need to be assertive without appearing impolite. Angela found it a problem asking people who were preparing meals for her what time the food would be ready, to avoid injecting too soon, and having to eat before the meal was ready. Tanya was aware that eating out could affect her adversely as her glucose levels could be high for as long as two days afterwards. Marge described the opposite problem where she would be offered meals with no carbohydrate content, which affected her blood sugar adversely in the opposite direction.

People used to cook diabetic jellies that tasted disgusting. And then you had the diabetic jams and marmalades, and they were full of sorbitol which gave you the runs ... some of my Swiss friends cook meals with little or no carbohydrate in, or minimal, which is quite interesting.

(Interview data Marge 826–829 and 833–835)

Other ways in which diabetes was raised as an issue related to driving, either due to a financial loading on an insurance policy, driving licence or a concern about the safety aspects of driving if hypoglycaemic. Several of the women referred to keeping their blood glucose levels high when they were driving to avoid hypoglycaemia. Irene referred to problems she had encountered in relation both to her driving licence and insurance, which were linked to her perception of how she viewed herself as an able bodied person.

I mean I had an ordinary driving licence for years, until we changed insurers or something, and they caught up with me and discovered I was a diabetic and I hadn't deliberately deceived them. I know I hadn't, but I'm pretty sure at the time when I filled in whatever form it was , and it was a long time ago of course, it probably just said 'are you disabled?' and I said no because I've never regarded myself as disabled.

(Interview data Irene 1345–1353)

Although Annette had stated during her interview that diabetes did not stop her doing anything, in her journal she made the following comment about driving, in relation to the fact that she lived in an isolated area. The following quotation demonstrates the contrast between the freedom that she perceived driving could bring to her life, and the unacceptable risk associated with this.

How wonderful to be able to drive – liberating (?). I could go to cities, libraries. I would have the facility to enable me to get a job, see people – this is a beautiful and caring place but it is so lonely. It would be wonderful to drive, but I never shall because of my diabetes. What would happen if I went hypo at the wheel? I might kill someone. I couldn't cope with that responsibility. I'll never drive.

(Journal data Annette)

- e) Problems with diabetes were reported as being linked to *other peoples' perceptions*. It was not necessarily the perception of the other person themselves

that was problematic, but more for the women with diabetes who were troubled about the impact on the other person, often a family member. Like Annette, Paula was concerned about the effect of waking her husband during the night if she had low blood glucose, and how when her glucose levels were unstable, her bad temper affected everyone else in the house. She was also concerned about her diabetes not causing problems for her mother when her father was dying, as she felt that her mother's focus should be on her father and not her.

Judith described other peoples' reaction to her diabetes, particularly her father in law who referred to her '*problems*', by which he meant diabetes. She went on to relate how her daughter made use of her diabetes.

Daughter's 17 and she's going through this mother daughter thing at the moment where she wants to be an adult but sometimes she wants to be a child and instead of coming out with that, it's my diabetes that is the problem. It's an excuse; it's always there to be picked off the shelf whenever she needs it.

(Interview data Judith 224–229)

When referring to problems with their diabetes, there was a sense of ownership and responsibility and a desire to prevent them.

If I keep doing blood tests, in some situations, then hopefully I can catch the problem before it actually becomes a problem, and deal with it, yes, there and then, which works much better than, letting it go to extremes. Yes, my diabetes does affect everything I do in life, every event, absolutely everything, but it doesn't stop me doing anything. It's never stopped me doing anything. Carry on regardless, I think.

(Interview data Annette 658-665)

Carol's view was that certain symptoms could indicate there was a diabetes related problem in the physical sense such as those relating to hypoglycaemia, whereas in

contrast Judith held the view that diabetes exaggerated all the other problems in her life. Although obstacles such as hypoglycaemia could be preventable, at times they became a reality which needed to be overcome as described in Section 6.2.3.

Carol, Lois and Josie all referred to diabetes as '*my problem*', indicating ownership and their responsibility in solving it, Jane expressed similar views with regard to the health care setting, relating how she was told she would not be able to have children after being diagnosed with diabetes, and in fact went on to have three. Irene referred to herself as not being thought of as a '*good diabetic*' (Interview data Irene 2223), but not a '*problem case*' (Interview data 2045), suggesting there was a perception of degrees of problems within diabetes care.

I do feel that I have got to keep a close eye on it and then it doesn't become a problem. If I don't keep a close eye on it then it does become a problem.

(Interview data Lois 769–771)

I get a guilt complex when it's time to go to the clinic and that, I suppose that affects it in a way, I feel I ought to be making more of an effort for them, and then I change my mind and think 'well it's my problem not theirs', they're only there to guide me.

(Interview data Jane 520–525)

It seemed that many of the above problems described in the above sections were caused by lack of control over something that belonged to the women (diabetes), and related to overcoming obstacles that were not necessarily caused by either the women themselves or their diabetes. They described feeling powerless to avoid the impact of problems on their diabetes, although not for the want of trying, and which they were in turn determined not to allow to control their lives.

Hassle

Four women referred to diabetes as a hassle – Carla, Carol, Jane and Janice, and was a term often used when describing relationships with other people which had an effect on the women themselves. Due to the small number of women directly referring to hassle, quotations have been included for them all. For Carla, '*hassle*' was the first word that came to mind when she thought about living with diabetes, although she qualified it with '*surmountable*'. She was a single parent to three children; she worked more than full time in a demanding professional capacity, and had a caring role for her ex husband who lived in the same house. Diabetes was an extra thing to add to an already busy life, and she strongly objected to the term '*diabetic*'.

Julie You said that you don't like being called a 'diabetic'?

Carla NO. I'm a person. I'm Carla and I happen to have diabetes.

(Interview data Carla 1252–1256)

For Carol the hassle referred to a stroke that she suffered which she believed to be due to her diabetes, and which she had difficulty getting the medical profession to diagnose.

It obviously wasn't a major stroke or I wouldn't have been able to function. It was enough of one so that I've never forgotten it and the hassle it caused, and I suspect that I've probably had a number of mini strokes.

(Interview data Carol 857–860)

Jane's hassle with diabetes also referred to health care professionals in terms of the barriers to receiving the appropriate help within the system, which she felt was improved since the employment of diabetes specialist nurses.

Well, it's like the diabetic nurses now, they've got this phone number for them and there's an answer machine. If they think you need to see the doctor they'll push you in for an emergency appointment, whereas before you'd sort of go back to your GP and it just seemed like a lot of hassle.

(Interview data Jane 609–614)

Janice's source of hassle was with the interference from members of her family.

And they say 'mum do you want something to eat?' 'oh no, shut up and leave me alone'.

(Interview data Janice 968–969)

Although only 4 women referred to hassle in relation to their diabetes, it was clearly an issue of importance to them – hence its identification as a theme. To me, Carla's whole demeanour was of a woman who was hassled. She referred to the untidy state of her house which she had no time to attend to. She was interrupted during the interview by her children asking her questions. She described a fraught day in the work situation, and she appeared tired and as someone who had little time to spend on herself. Carol's recollection of the period around the time that she was diagnosed with a stroke was communicated in an angry way, as she recounted the frustration she experienced at not being able to convince the health care professionals that she had suffered a stroke, and that she was aware of the reaction of her own body in a way that health care professionals could not be.

Bother

Bother was the third theme identified as a constituent theme of the major theme of Diabetes as a Nuisance.

Fourteen women referred to bother in relation to diabetes – in three ways - how it was a:

- a) Bother to self,
- b) Bother to others, and
- c) '*Can't be bothered*'.

- a) ***Bother to self.*** At the beginning of her interview Lesley was clear that having diabetes did not bother her. However, as the interview progressed, there was a change in her view, for which she viewed the interview as a catalyst, as her awareness was raised.

It really doesn't bother me. That's the control I have over it. It doesn't bother me and it doesn't control my life, so I carry on regardless I suppose.

(Interview data Lesley 192–195)

I suppose talking to you, you know, there's more things coming up and things that do, sort of, bother me, but nobody asks that in depth sort of questions. It is just, you know, you know that they don't want to know that much.

(Interview data Lesley 374–379)

- b) ***Bother to others.*** Of those women who referred to bother, the majority were concerned about the bother their diabetes caused other people. In terms of close relationships Carol referred to her brother and her mother. Mealtimes were difficult times in their house as a child, and Carol recalled that she was '*expected to be perfect*' (Interview data Carol 23–24), and mealtimes often culminated in emotional outbursts. But it was her mother who she regarded as being most bothered by her diabetes who regarded it as '*another cross for her to bear* (Interview data Carol 21)', perhaps as a result of feeling a failure for having produced two children with medical conditions (her sibling being deaf). Gina referred to the fact that her father had recently become bothered by her diabetes, particularly in respect of her diet, and Claire stated that she felt her sons were

bothered, for two reasons – they were concerned about her health, and also that they might develop the condition in the future. Marge reported that although her friends were not bothered by her diabetes, her husband was, and she found this difficult to cope with, and as a response she relinquished control of her diabetes to him on occasions. This had made situations worse when she allowed him to take over, as the *'whole thing falls apart'* (Interview data Marge 166). In general she tended not to react to what she perceived as his interfering, as she found that this led to hypos due to her using excessive emotional energy.

- c) ***'Can't be bothered'***. Other women referred to not being bothered with their diabetes at different times. Joy and Marge both referred to not bothering to consult health care professionals- Joy because she felt she was fobbed off and not given satisfactory answers to her questions, and Marge because she felt that their knowledge was lacking. Similarly Mandy reported not bothering to look for information on the internet any more as she was no longer motivated to learn more about her diabetes. In terms of everyday living with diabetes Judith reported not bothering to test her blood glucose levels if they had been satisfactory the day before; Joanne did not bother with her urine testing, and Irene did not bother with swabbing her injection sites. Carmen allowed needs in her daily life to take priority over her diabetes.

Diabetes itself could have an effect on the women's motivation to manage their diabetes, and Lynn reported that high blood glucose levels affected her motivation.

To say it all in a nutshell, there's times when it just gets you down and you really can't be bothered.

(Interview data Lynn 1786–1787)

Jane described taking this to a point where she did not even inject, and subsequently became seriously ill.

Pain

Diabetes was described as a '*pain*' by seven women and largely referred to the lack of spontaneity associated with living with diabetes. Josie referred to it the most frequently, and it was the first word that came to mind when she thought about living with diabetes, and it was evident from her demeanour that she was thoughtful and sad.

It's a pain. (PAUSE) Just freedom, your freedom's gone, to me it is. I hope I'm not sounding too dramatic, but yeah, my freedom's gone. I can't just do anything.

(LONG PAUSE)

(Interview data Josie 85–87)

She expanded upon this by referring to the constraints imposed upon her life by eating at particular times and the ensuing fear if she was somewhere without food or glucose, or eating out socially later in the evening. She spoke of the potential for going on holiday to be a pain, but her husband had taken over the organising role to minimise this for her, emphasising her passive role in managing her diabetes. Holidays and social events were also identified as a pain by Pam, in terms of having to remember to take all her monitoring and injection equipment with her. Not being able to go out for a meal spontaneously was also a pain for Paula as she felt unable to do so in case there was a wait for the food. Marge found blood testing a pain, particularly in the morning as this was when she was busy with her animals. For Judith it was the health care system that was a '*pain in the neck*' (Interview data Judith 494), especially the lack of continuity of care, and just having to remember to go to clinic appointments.

Lynn was more upbeat. Although she found diabetes to be a pain she expressed a generally positive view.

It's not that bad, it can be a bit of a pain but it's not that bad, and there's no need to worry about it. It's not the end of the world.

(Interview data Lynn 637–639)

Irritation

Six women referred to diabetes as an irritation, but Angela and Claire appeared to find it more so than the others. Both were women from professional backgrounds, Claire on the brink of early retirement, and Angela had retired but was still engaged with voluntary work. Claire was irritated because she was searching for answers and reasons for her unexplained hypoglycaemic attacks, and could not find a pattern. She wished to control her own life without outside intervention, and was irritated because she felt that she did not deserve to develop diabetes.

I think there is that perception, that it's this strange disease that the public aren't fully informed about. I mean I wasn't myself, I suppose I never dreamed I could get it because I totally thought it was hereditary, so that, you know, that was the thing that shocked me, and I did do quite a big trawl in my family and I went back as far as any of the relatives know, nobody in either side of my family have ever had it, so you then think 'God, I'm the start' and 'is it going to happen to my kids?' and all the rest of it, so that's the kind of irritation that I feel about it, that if I was hugely overweight, or I'd led a debauched life, there might be some justification, but just being obviously genetically susceptible was enough.

(Interview data Claire 212–225)

Angela also had an arthritic disease, and she viewed diabetes as '*just another irritating complication to deal with*' (Interview data Angela 172). She was irritated by not being able to do what she wanted to due to being tired and stressed, and needing to input extra effort and thought into a situation. Her other irritation was with health care professionals, as she had difficulty obtaining the correct dose of insulin when she was in hospital. Irritation with health care professionals was also expressed by Marge as she had difficulty obtaining medication from her local health centre, and was also aware of a breach of confidentiality regarding her diagnosis to another patient in the practice. Mandy also

expressed irritation at being told in a public situation that there was a nurse available should she need medical intervention.

Carol’s irritation centred on meals being delayed when eating out and being dependent upon such a tight schedule, and Lois referred to a physical irritation caused by cold sores which had a tendency to develop when her blood glucose levels were high.

The 5 constituent subthemes of the major theme of diabetes as a nuisance have some shared characteristics with each other, as well as some divergent features. All represent a degree of interruption to the everyday lives of the women to a greater or lesser degree. Although difficulties and problems share similar characteristics, the differences relate to their focus. Many of the difficulties described as being experienced by the women relate to issues such as self – management, complications of diabetes and emotions – all of which can be described as having a personal focus. In contrast, obstacles have a more external focus and include issues with relationships with health care professionals and work and other social interactions.

Table 4.4 demonstrates how the major theme and constituent subthemes identified were distributed among the women interviewed.

It can be seen from the table that for some women i.e. Carol, Lynn, Jane and Marge, the majority of these themes were identified. For others i.e. Josie, Tanya, Janice, Carmen and Annette, only one or two were identified. However, a note of caution is necessary here, as quantification of qualitative data can give a false picture. In this case, it illustrates only the occurrence, and not the intensity, of themes emerging from experience.

However, the accounts of the experience of living with diabetes in relation to its nuisance value suggest congruence between the occurrence and intensity of the themes identified.

Table 4.4 Distribution of themes across women interviewed

		Nuisance	Difficulty	Obstacle	Bother	Pain	Irritation
1	Carol		✓	✓	✓		✓
2	Lesley		✓	✓	✓		
3	Josie			✓		✓	
4	Lois		✓	✓	✓		✓
5	Gina	✓	✓	✓	✓		
6	Joy	✓		✓	✓		
7	Pam		✓	✓		✓	
8	Carla	✓	✓	✓			
9	Angela		✓	✓			✓
10	Lynn	✓	✓	✓	✓	✓	
11	Irene	✓	✓	✓	✓		
12	Jane	✓	✓	✓	✓		
13	Tanya		✓	✓			
14	Claire		✓	✓	✓		✓
15	Judith		✓	✓	✓	✓	
16	Paula		✓	✓		✓	
17	Joanne		✓	✓	✓		
18	Joan	✓	✓	✓		✓	
19	Janice			✓			
20	Marge	✓	✓	✓	✓	✓	✓
21	Carmen				✓		
22	Mandy			✓	✓		✓
23	Annette		✓	✓			

Examination of the data relating to the subthemes of difficulty and obstacle suggests a struggle or conflict between managing the demands of diabetes and those of everyday life with sometimes serious effects. Carol refers to '*struggling*' (Interview data Carol 758) 'with her insulin injections every morning, and Carla to '*struggle*' (Interview data Carla 109) and '*confrontation*' (Interview data Carla 1291) with health care professionals, highlighting both internal and external aspects. The data relating to the subtheme of bother indicated that bother relating to diabetes had the potential to be wide ranging as it affected both the women themselves and other people in relation to their diabetes. Irritation suggests that diabetes is something that the women could have done without, but caused minor inconveniences rather than major issues. Diabetes as a pain again suggested minor inconvenience requiring some action to alleviate it, but again without serious consequence. The one woman who used the word, but in a different context to others was Josie, for whom diabetes was a major issue with which she had not come to terms.

In conclusion, the women's accounts have illustrated the association between the five subthemes and the major theme of diabetes as a nuisance. There was an acknowledgement of the nuisance aspects of diabetes and the potential for outcomes that could be anything from mild to serious. A desire to be in control was demonstrated and much of the nuisance value can be attributed to feelings of inability to take and maintain that control. However, being out of control did not seem, for the most part, to be a major feature of living with diabetes, although some women were affected more than others by this. In spite of the nuisance, a stoical stance was described, with the emphasis on the positive, rather than the negative. Lynn sums this up when she says:

I think it can be a pain in the backside, but it's not the end of everything. People have said since I've been a diabetic, people have said 'you poor thing', and it annoys me because why ...,? I often think why are people so shocked to know that they're a diabetic, or going on insulin, because it's not the end of everything, you can still enjoy yourself?. You've just got to learn to find the middle and the

right balance. Well I always think there are people worse, if I want a moan I'll have a good moan, but at the end of the day I think why should I moan? There are people that are worse off.

(Interview data Lynn 1687–1695)

From the initial reading of the transcribed data there was a sense of diabetes being another thing for women to deal with in the context of their busy everyday lives, something that women attempted to relegate to the back of their minds, but which kept interfering with their normal functioning – a '*nuisance*' in effect. As a result of this, the initial thematic analysis was undertaken using the occurrence of the word '*nuisance*' in the interview data of eight women as its starting point. The analysis was then expanded to include other words and narrative accounts which seemed to relate to the concept of '*nuisance*' as described by these initial eight women. The resulting constituent subthemes (1 major and 5 subthemes) have been discussed above. However, this was only the beginning of the analytical process. With these themes in mind, the interview and journal data were then scrutinised for narrative accounts of stressful events in relation to living with diabetes, where diabetes became a nuisance. Comments and emotions relating to these have been incorporated into the following poem in this chapter, and the next two chapters also consider this.

4.3 Poetic representation of diabetes as a nuisance

The following poetic representation of the theme of Diabetes as a Nuisance has been created as a result of integrating fragments of data into a whole. No claims are made as to the literary quality of the poetic form – it is a poetic representation of research findings. The use of poetic representation in Interpretative Phenomenological Analysis is an emerging form, and can be viewed as contributing to the further development of the methodology in a relativist, rather than a realist stance (Sparkes, 2009).

In common with Glesne (1997), Sparkes and Douglas (2007), and Richardson (2000), data from in depth interviews has been transformed into a poetic representation. Single perspectives have been reformed into a multiple one (including mine). Although none of the words are mine as the actual words of participants are used in the poetic representation, the decisions regarding the ordering and structure are, and are influenced by my readings of interview and journal data, in an effort to make the personal public, resulting in a shared understanding of the women's experiences. Richardson and Adams St Pierre (2005) refer to writing as a method of analysis and interpretation, and intellectual and emotional activity and the researcher cannot be separated in qualitative (and arguably quantitative) research. The aim was to create an interpretation that causes an emotional, as well as an intellectual, response- to provide a window into the experience of someone else and to engage senses other than the cognitive within an active, rather than a passive experience (Rapport and Sparkes, 2009). The resulting distillation of a large amount of transcribed data from survey, interview and journal data retains the voices and messages of the women themselves, in keeping with the feminist stance taken within this study. The first person has been used to enable identification with that experience. The poetic representation can be conceptualised as data in itself, an interpretative device and research dissemination tool, allowing for a range of interpretations by the reader from their own standpoint (Barrett, 2011). In this chapter the '*Humpty Dumpty*' problem is reversed. A representation of the whole is given initially, and is followed by an IPA analysis of the interview data into themes that together make up the representation of '*Diabetes as a nuisance*'.

Diabetes is a nuisance

It's a bit of a nuisance.

I'm bored with it – being sensible. Regime; balance; control; be careful; take care; low fat foods; don't drink too much

Routine; organisation and planning; diet and food; monitoring and testing

An inconvenience; an irritation

A dirty disease – I'm not that kind of person.

It's not the end of the world; it hasn't really affected very much

Positive; gratitude; confidence and support

Lucky it's not other things – but it's something I could do without.

It's a bit of a nuisance.

It's a blooming nuisance.

*Hassle, but surmountable; a worry; an excuse; annoying; it's a pain
Out of control; high sugar level; thirsty; no cream cakes; having fights
with the kitchen floor*

Really bad tempers; needles and injections

Sword of Damocles; luck; help! I can't relax

*A high nuisance value – but it's given my life some shape. I don't know
whether I'd be happy without it.*

Not a great burden; still a nuisance; a damned nuisance

Something I've got. What have I done to deserve it?

It's a blooming nuisance.

It's a bloody nuisance.

Shit; hypo; frustration; fear; foolish;

Wrong; no choice; restriction

Constant pressure; stress

Burden; dark cloud; prejudice

Just freedom. Your freedom's gone- I can't just do anything

It's a bloody nuisance

But it's part of me.

Denzin (1998, p. 226) states that 'good poetry always brings a situation alive in the mind of the reader'. That is also the aim of the poem, without detracting from the '*the emotive, contextualised and powerful messages of the original text*' (Rapport and Sparkes, 2009).

Their powerful poetic construction of the experiences of a woman survivor of the Holocaust, reflects these principles, and can also be applied to this study as the women with diabetes may be viewed as survivors, albeit in a very different context. Although they may not be physically confined, diabetes may be seen as a metaphorical constraint.

As Lorde (2007, p. 36) states in relation to the power of poetry, *'poetry is not a luxury. It is a vital necessity of our existence. It forms the quality of light within which we predict our hopes and dreams towards survival and change, first made into language, then into an idea, then into more tangible action. Poetry is the way that we give name to the nameless so it can be thought. The farthest horizons of our hopes and fears are cobbled by our poems, carved from the rock experience of our daily lives.'*

The essence of this chapter is the interpretation and meanings the women gave to diabetes and words from all 23 women interviewed have been incorporated and included verbatim in the poem. The bulk were taken from the responses to the interview question 'what words come to mind when you think about living with diabetes?', with verbatim extracts from the rest of the interview data where 'nuisance' was referred to. The poem is a co constructed compilation of the words of all the women interviewed, which has been decontextualised, and will be recontextualised in subsequent accounts of their experiences of living with diabetes.

Hypoglycaemia as a nuisance was a recurring theme throughout the data and will be examined in Chapter 5. During the course of the research I witnessed two women have hypoglycaemic attacks, and an account of these is also included in Section 8.2.2.

Diabetes as a nuisance

Eight of the 23 women interviewed directly referred to diabetes as a nuisance, and their depictions ranged in relation to the intensity of the nuisance from *'a bit of a nuisance'* (Interview data Gina 1711) to *'a bloody nuisance'* (Interview data Irene 1078). This

suggests the intensity of the nuisance as being a continuum, with slight inconvenience and major disruption at opposite poles.

Within the poem, the first stanza refers to the impact of diabetes as a nuisance at the slight inconvenience end of the continuum. Being sensible, and following a healthy regime could refer to the majority of health advice given, but diabetes adds an extra dimension in terms of planning and monitoring of blood glucose levels. On a day to day basis, diabetes is little more than an inconvenience, which does not impact upon life to any great degree.

So diabetes is a nuisance, but it doesn't stop you from doing things. You can go mountain climbing, swimming, sailing; you can do whatever you want as long as you're careful with your sugar.

(Interview data Joy 207–210)

Tanya's description of diabetes as a '*dirty*' disease in the first stanza was founded upon her perception that people who had diabetes did not take responsibility for its management and were therefore not in control, which was at odds with her own self-image as a responsible woman who was very much in control. Cancer would not have been perceived in the same way, it was a '*good*' condition as people were sympathetic because it was seen as being serious, unlike diabetes. Cancer was something over which a person had no control, whereas the progression of diabetes was dependent upon behaviour. However, her view had changed since diagnosis to a much more positive one. Like any inconvenience, however mild, diabetes was something that could have been done without.

The second stanza represents a progression towards the opposite end of the continuum, a major disruption. The impact upon daily life was increased, with a greater degree of inconvenience, but was manageable for the most part, with periods of major disruption. Whereas the first stanza is concerned with being and remaining in control, this stanza identifies periods and events where the woman may be out of control, due to

impaired blood glucose levels resulting in hyperglycaemia or hypoglycaemia. There was a feeling of being on alert, both in the long and the short term, for the complications of diabetes to develop, sometimes without warning in the case of hypoglycaemia and the development of long term complications. A feeling of being subjected to fate was suggested in the sword of Damocles imagery, where a sword was suspended by a single hair above Damocles' head, a metaphor for disaster which may occur at any time. However, in spite of diabetes being a nuisance, for some women who had been diagnosed for many years, it offered a degree of structure and security to their lives, but which was occasionally challenged by unexpected events as discussed in Chapter 6.

The final stanza refers to the opposite end of the continuum, where life is defined by diabetes. Negative emotions and feelings are identified, and there is a sense of relentless progression. The words represent an element of even going beyond being out of control, to a resignation of fate and a poor outcome. With the lack of freedom comes a sense of imprisonment and helplessness, a life sentence from which there is no parole. The following quote illustrates Josie's passive approach to her diabetes in terms of being able to influence the progression of her condition.

I don't like it, I don't want it and there's nothing I can do about it 'cos it won't ever go away, you know, unless you perhaps have a transplant or, you know, have bits and pieces removed, but no and I've got it for life, but I don't like it. So.., not an awful lot I can do.

(Interview data Josie 11–14)

The final line of the poem depicts that in spite of the nuisance of diabetes, it is an integral part of life – a companion in every eventuality, and can have various functions which may sometimes conflict with each other – '*my friend, enemy, support and teacher*' (Journal entry Tanya 1st August). However difficult things may be, diabetes needs to be managed in order for the woman to survive, as it is an integral part of life.

In a stressful situation, however stressful the situation, you're still diabetic and you've still got to do these things that are really a bit of a nuisance but you've got to do them, so I suppose it's a sort of a thing that you've got to keep a little bit back, you can't freak out completely 'cos you've got this little part of you that says 'now come on you've still got to eat, you've still got to have your injection', so there's that.

(Interview data Gina 1708–1716)

This data analysis chapter has begun to address the complexity within the research questions posed, particularly in relation to the question *'How do women with insulin treated diabetes interpret and manage their lives?'* The following two data analysis chapters continue to do this, and also address the questions *'what do women describe as stressful in relation to their insulin treated diabetes?'* and *'what impact do these stressors have on women's lives?'*

The following chapter is concerned with the theme of Diabetes in Daily Life – a superordinate theme common to all the women's experience of living with diabetes.

CHAPTER 5

Diabetes in daily life

This chapter focuses on the usual everyday experiences encountered by women with diabetes. It will show how these experiences were affected by diabetes and vice versa, and what was experienced as stressful within that daily life. This is in contrast to the evidence reported during times of crisis and how they disrupt those daily lives, which will be the focus of Chapter 6.

As identified in the interview schedule (see Appendix 3) questions were asked relating to stressful situations in their daily life. Participants were also asked to describe a typical day in their lives. Data has been examined from these responses, which was then categorised and used to construct a model of everyday living for a hypothetical woman with diabetes. This is followed by exemplars of how daily life and diabetes interact, one from each woman, with a view to providing an examination in both breadth and depth of their experiences in a number of different areas of life.

Analysis of the data demonstrated that there were three main issues relating to diabetes within daily life: a) monitoring and treatment regimes, b) eating patterns, and c) the ever present potential for hypoglycaemia to occur.

The first section of this chapter will describe a typical day, constructed from data from all the women interviewed, and, in keeping with IPA methodology, the experiences of individual women are used as exemplars. The conclusion was that the women were required to do all the activities that any other woman would do during a day, but also

needed to be constantly vigilant to their needs in relation to diabetes management, and at times engaged in risky behaviour in relation to the management of their diabetes.

5.1 A typical day

All of the women were able to describe a typical day in their lives, which for some was a working day, and for others was a non working one.

The day started sometime between 5.30 and 9.30. Those that still had children at home, woke them and chivvied them along if it was a school day. The next hour or so was taken up with checking blood glucose levels, injecting, breakfast, showering and leaving the house if it was a working day. If they were in a hurry, blood glucose testing, injecting and eating were sometimes forgotten or deliberately omitted, thereby putting them at risk of either hypo or hyperglycaemia.

The first part of the morning was taken up with work related activities – either inside or outside the home; daily chores; gardening; shopping; study or social activities. A mid-morning break with food was an important aspect of the morning, as this was a time when there was an increased chance of blood glucose levels dropping, as the morning injection reached its peak intensity. For those women working shifts, mid-morning sometimes became lunchtime, and sometimes required an additional injection of insulin if they were on a four times daily injection regime.

Most women ate between 12 and 1pm, and again needed to check their blood glucose levels and possibly inject again, which was also forgotten at times. If lunch was eaten away from home or at the workplace, either it had been prepared to take as a packed lunch, or eaten at a restaurant, where it was sometimes difficult to calculate the amount of carbohydrate and amount of insulin needed. The afternoon was again taken up with similar activities to the morning, with a midafternoon snack (and sometimes a sleep)

being seen as a priority, again to avoid hypoglycaemia. Most women were home between 5 and 6 in the evening, and were involved with preparing the evening meal.

Evening activities included catching up with household jobs; personal exercise (sometimes with blood glucose levels being checked before and after); driving children to evening activities (checking blood glucose levels and eating beforehand); dealing with domestic animals and horses; preparing for the following day; social interests, and watching television. Hypoglycaemia was a potential problem if too much exercise was undertaken or large amounts of alcohol consumed. Blood glucose levels were checked before bed, and another snack eaten. Most women went to bed between 10 and 12pm. Chocolate bars were sometimes kept under the mattress in case of night time hypoglycaemia, sometimes due to sexual activity.

The tone of this typical day is one of routine and planning in relation to management of diabetes, which Claire described as '*embedded*' (Interview data Claire 12 and 1007).

However, management of diabetes related needs occurred in juxtaposition to the needs of fulfilling roles within the women's social context such as work related roles and interactions with other people.

In relation to work, Joanne adapted her evening meal pattern. The afternoon snack became the first part of her evening meal if she was working, as she worked an early evening shift, and she ate twice and split her insulin dose between the two meals. Judith injected, and then went to work, delaying breakfast until she arrived there. She deliberately manipulated her insulin dose to suit her needs – she was prescribed a four injection daily regime, but chose to usually only inject twice, and supplement if she needed to. Having had diabetes for seventeen years her reported view was that she was the person best placed to manage her insulin regime in the context of her life. Josie injected, showered, and then ate breakfast whilst getting ready for work. Both of these actions increased the risk of hypoglycaemia. Jane reported sometimes missing her

injection, and then having a dry mouth and being thirsty later in the day, symptoms of hyperglycaemia.

In terms of other people affecting the daily routine of managing diabetes, for two of the women, Carol and Paula, it was their husbands who had the most impact. Paula rose at 5.30 because that was when her husband woke, and he liked to chat. She subsequently went back to sleep until 8 when he had left for work. Both Carol and Paula had husbands who returned from work later in the evening, and they waited to eat with them, meaning that they snacked beforehand, which increased their weight gain. To compensate, Carol was on a very low calorie liquid diet during the day, and suffered frequent hypoglycaemia.

Claire reported hypoglycaemia in the work situation as embarrassing and disruptive as her role involved teaching, and for Annette, avoidance of this was a priority as much of her work involved meetings with other people. Another aspect of her work required her using the telephone to communicate, and she was concerned about the impression that might be given to someone who had not met her personally.

All of the women, with the exception of Joan, described active full days, and this was apparent when I visited them in their homes (with the exception of Josie who was interviewed in the workplace). Joan's experience was very different, and represented the most extreme of the deviation from the experiences of the other women. When I visited she was sitting in a darkened room, and had the demeanour of someone who was very tired, bored and lacking in energy. She awoke late in the morning, and described a day of sleeping, eating and injecting insulin. She rarely left the house. She described her evenings as being more active in that she had visitors, watched the television and used the computer. She would usually be awake until 3 am. She described her days as monotonous and depressing, and contrasted them to the days when she was active and working, prior to the time when she started to develop long term complications of diabetes. She had been taking insulin for thirty nine years.

Paula found a day at home more stressful than being at work, whereas Josie preferred being at home. Emotions described ranged from being happy and satisfied with the day to tired, grumpy and depressed, and the description of days ranged between normal '*too normal for comfort*' (Interview data Carla 199), boring and ordinary to tense and strained. Marge described a decent day as one '*with no disasters*' (Interview data Marge 550). A sense of being driven by time and the clock was apparent from the women's accounts, and although things were sometimes forgotten, diabetes was a factor in the planning of the day and was in the minds of the women, and diabetes responded well to a more structured day. Paula reported that each day was usually structured in a similar way to the next, and how deviating from her usual routine could affect her life with diabetes and her feelings in relation to that. However, her experience was not typical of the women's experiences in general, but was influenced by her husband's demands on her, which was another factor for her to take into account when addressing her own needs. A lack of assertion and confidence is illustrated in the quotation below. As well as attending to her own needs, she attended to the needs of other household members, sometimes putting her own needs second.

Paula I suppose in lot of ways I feel like I've run to a clock the whole time, but that's probably basically due to me anyway, though the going to bed at 10's definitely not because I used to, when I was living at home, used to end up going to bed about 1 in the morning, but it's just you get used to what he (husband) needs, and he does need to get to bed early.

Julie And when you say you run to a clock most of the time, for what reason?

Paula Because of the diabetes. That does drive me mad. There are times when I really would like to just ..., my husband will sometimes say 'why don't we go out for a meal Saturday night?' and you think 'oh God if we do that, I've got to take all the stuff to do a needle in case we get stuck if you can't book a table and you've got to queue, you don't know'. I much

prefer doing an injection here and not having to cart everything with me. But it does mean that your life's not normal. You should be able to just feel like going out for a meal, and going, but sometimes that gets me down a bit, and I think 'you know. You should have times where you say I don't think I'll cook tonight we'll just go up the road and go for a meal', but I always think 'oh no, I've got to think will I need to take this, will they want us to wait for an hour and I won't have time to wait that long', so it is a bit of a pain.

(Interview data Paula 1000–1029)

The following section examines individual accounts from all of the women interviewed, in keeping with the inclusive nature of this study.

5.2 Interaction between daily life and diabetes

Data analysis identified the following themes, all of which were apparent in every participant's account of daily life and diabetes.

- Work (paid or unpaid) and study related
- Relationships
- Social activities
- Roles in daily life

Figure 5.1 illustrates the relationship between the constituent subthemes which were a part of the major theme of diabetes in daily life, and with the major theme itself.

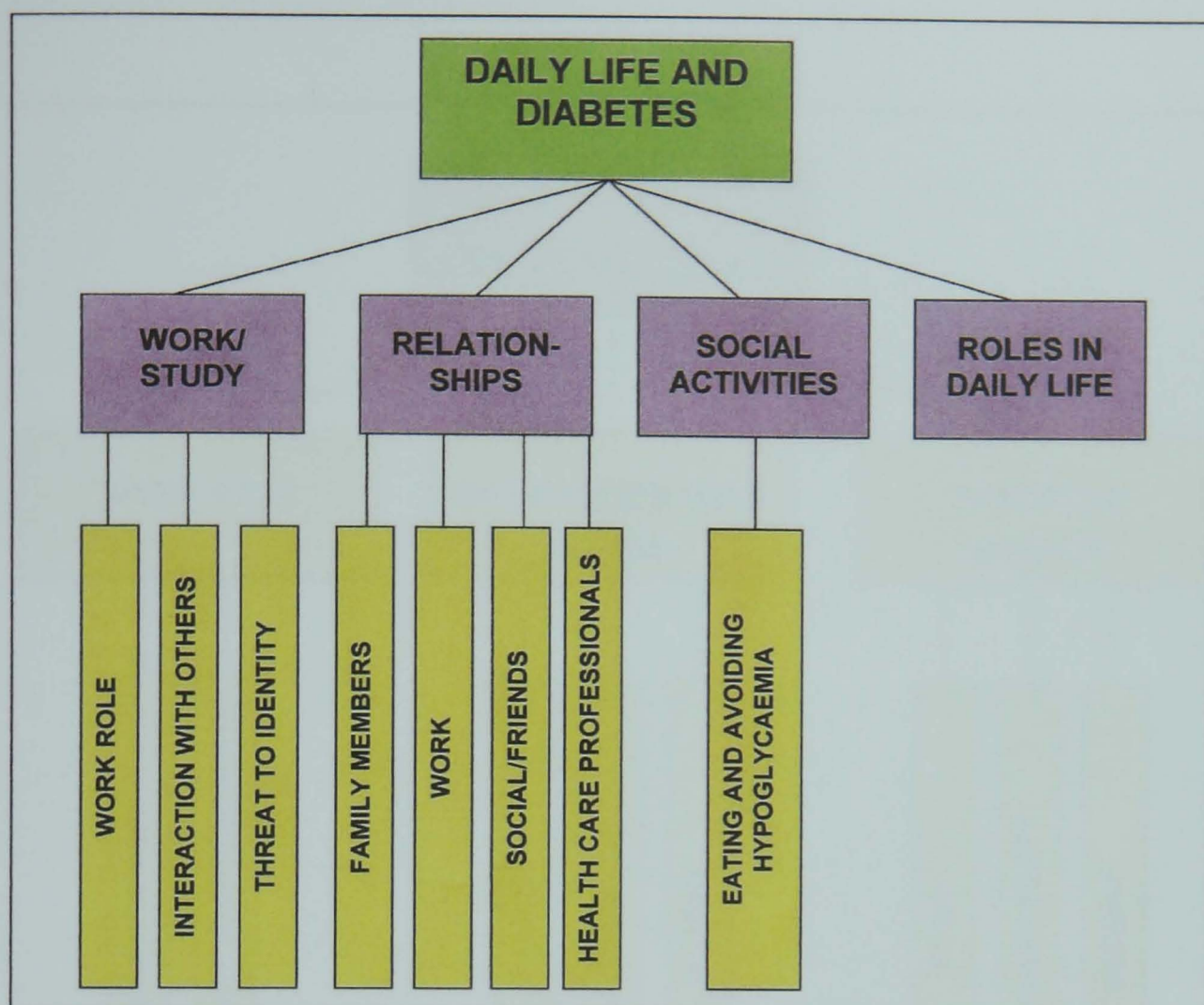


Figure 5.1 *Daily life and diabetes*

This section explores situations in the women's daily lives where everyday events and factors impacted upon their daily life and diabetes. In keeping with the feminist empowerment theoretical position, every woman is profiled in this chapter in relation to the category that was interpreted as being most relevant to her from the interview and journal data in terms of diabetes in daily life. The exception to this is Annette, whose account closes the section, as she stated that she found many things stressful about living with diabetes, and it was difficult to allocate her reported experience to one particular category.

5.2.1 Work and study related

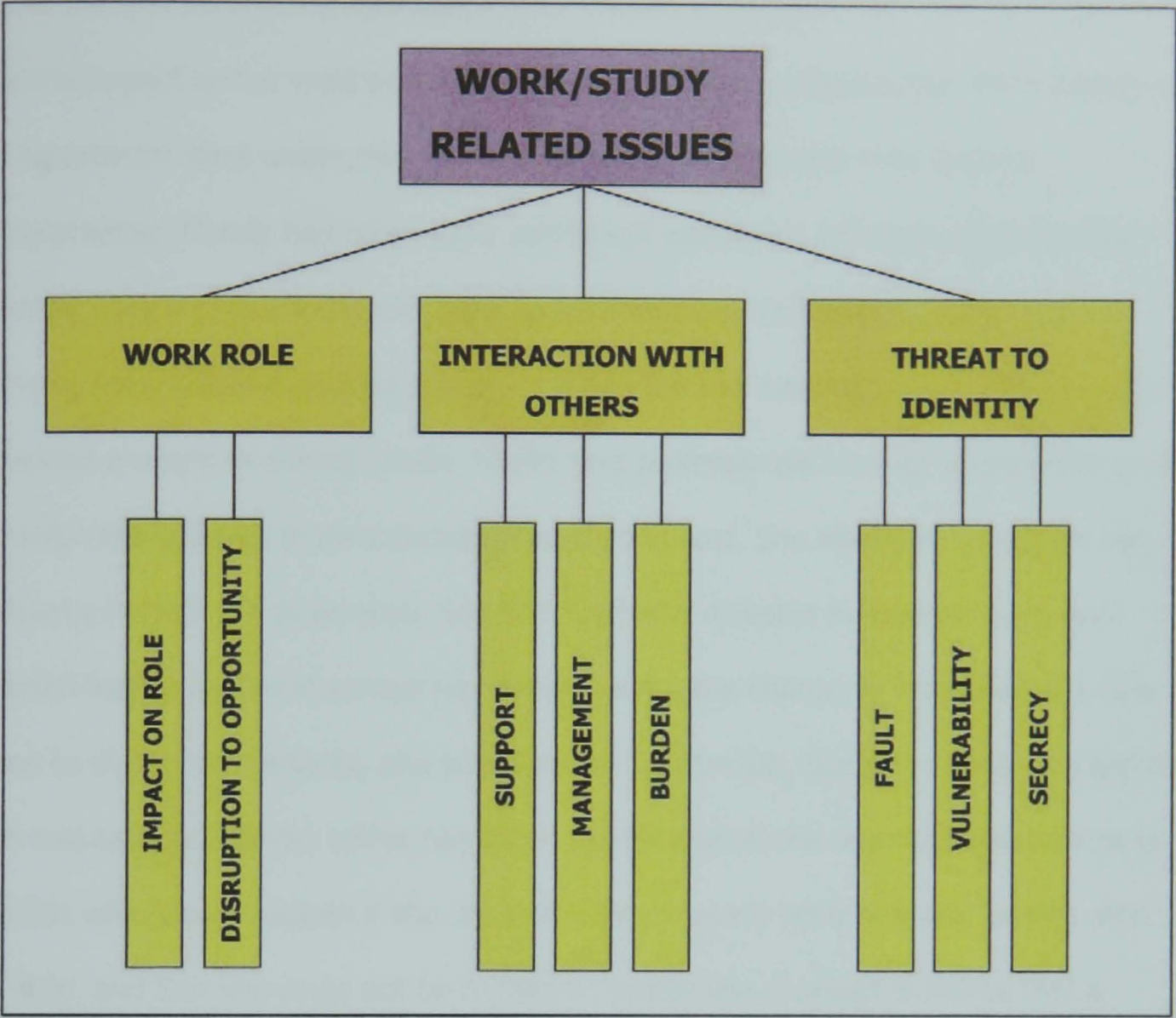


Figure 5.2 Subthemes of work and study related issues.

The identified constituent themes of the work and study related issues are: a) work role, b) interaction with others and c) threat to identity.

- a) The theme **work role** refers to the impact of diabetes on the work role, specifically in relation to hypoglycaemia and disruption to opportunity.

Work role

Claire worked in a teaching role in a large institution. She described herself as being someone who liked to be in control, and did not want to be seen as the person with the problem (meaning her diabetes) in her department. Her view was that there was an interaction between her diabetes, work role and relationships within that role. She was

aware that diabetes had the potential to impact upon her professional role. Similarly she described how her work could impact upon her diabetes, an example being if she did not stop to eat and became hypoglycaemic as a consequence. Josie also reported diabetes' potential impact on her work as an administrator in a large organisation. Most people in her department were aware that she had diabetes, and that she may become hypoglycaemic. Mandy had taken early retirement which was indirectly related to her diabetes, from a professional role. She had suffered severe hypoglycaemia, after changing from animal to human insulin, and had lost her warning signs.¹ Although she requested a return to animal insulin, health care professionals had not allowed her to do so, which she believed to be a decision based upon cost. She attempted to adjust her regime by herself, but to no avail. She had lived with diabetes for twenty years and reported feeling unable to control her diabetes since the change to human insulin. She began to suffer panic attacks, and subsequently left her job. Some time later she applied for a role as a childminder within her home. In her journal she reported being asked to describe what would happen if she became hypoglycaemic while she was looking after the child, and that she could not be registered unless she provided evidence that a neighbour would look after the child until she fully recovered.

I suggested that she should find out about diabetes but decided not to proceed as she (social services inspector) would be visiting me every six months, which would have driven me bonkers!

(Journal entry Mandy 18th September)

Disruption to opportunity and *impact on role* were identified as two of the themes clustered to create the theme of *work role*.

¹ Because the structure of genetically engineered human insulin is identical to that of naturally occurring human insulin, there is much less likelihood of antibodies being produced. Earlier insulins were derived from bovine or porcine sources and antibodies to these were produced when injected. This had the effect of delaying the action of the insulin. Many people reported rapid onset of hypoglycaemia when their regime was changed to human insulin, and also the loss of the warning signs that it was about to occur.

Diabetes had also affected Jane's work, in that she had not continued to pursue a nursing career due to concerns about hypoglycaemia. She had been diagnosed with diabetes as a student nurse twenty six years ago. Since then she had undertaken a variety of part time administrative jobs, rather than have a career following the diagnosis, as it was more compatible both with diabetes and family responsibilities. Although she did not feel that diabetes had impacted upon her performance in these jobs, she did feel that the jobs had impacted upon the diabetes. She was required to work across lunchtimes on occasions which affected her blood glucose control, and as a result had changed her insulin regime to four injections a day instead of two, to enable her to gain tighter control. Unlike Josie, she did not hide her diabetes from her colleagues. Although she had thought of returning to nursing, she made the decision not to do so as she had doubts as to whether she would be able to cope due to her diabetes.

It's always there, it's like a little black cloud, you sort of think ' well I can't really see myself doing that particular thing because of it.

(Interview data Jane 277–279)

Hypoglycaemia in the work place led Janice, who had been taking insulin for twenty five years, to retire from working outside the home. She took an early retirement package, which actually suited her very well, as she wished to leave, suggesting that diabetes had had a favourable impact by enabling her to do so. She reverted to giving private tuition inside the home, and although she still experienced hypoglycaemia, it was much more manageable, as she was her own boss. She was able to manipulate her timetable to allow her to rest if she needed to. She found social events more stressful.

So I think I do worry about hypos, if I go out for the day I'm worried about, is it time to have lunch? I've got to have lunch by such and such a time, and so perhaps I'm not as relaxed as I could be about just going out and have lunch whenever you feel like it. That's one of the problems I think.

(Interview data Janice 55–60)

Shortly before she was interviewed Gina, who had also lived with diabetes for twenty years, had moved to a less demanding administrative role. In contrast to Josie and Jane, Gina viewed her work as impacting upon her diabetes, rather than her suffering from work related stress. Stress impacted upon her diabetes by causing a rise in blood glucose levels, and her way of coping was often to leave the work situation for a short break. She had been able to avoid diabetes impacting upon her work, by undertaking roles that allowed her a degree of flexibility to manage her diabetes, rather than traditional administrative office based roles. She could only remember having had two days sickness absence relating to her diabetes, and related that to a time in her life when there had also been other pressures discussed in Section 6.3. Like Jane she had wanted to be a nurse, but had not pursued this. She did question whether diabetes was the only reason for making this type of decision.

When I was younger I had opportunities to sort of go abroad and do things, and, but, and I've often thought , I mean I said I couldn't do it because of my diabetes, but I think afterwards when I thought about it seriously, it wasn't because of my diabetes really, it was opportunities I just turned down because either they were a little bit scary or I hadn't got the confidence to take the opportunity , so I can't really say it was because of that, I think it was more I used it as an excuse it wasn't really a reason at all.

(Interview data Gina 217–226)

Joan had lived with diabetes for thirty nine years and although she no longer worked in a paid professional capacity she was studying for a degree. Taking examinations was extremely stressful for her. She had previously struggled to obtain a pass grade, and talked about her fear of failure. She described herself as '*putting herself through it again*' and feeling out of control. She reported that the stress of the examinations resulted in increased blood glucose levels, which she corrected by giving herself an increased insulin dose.

- b) The theme ***interaction with others*** refers to support received from others in the work place, interaction with management and diabetes as a burden. These themes were clustered to create the theme of *interaction with others*.

Support from others

Claire had few close relationships, but was able to trust one particular person who had also been recently diagnosed with diabetes. Claire referred to her close colleague as her 'carer' (Interview data Claire 1249) as she would be unaware of her blood glucose dropping and he would suggest that she stop and eat some carbohydrate. He was the person who she would advise the students to turn to for help if they were concerned about her.

Interaction with management

A new manager joined the department in which Josie worked, who was not aware that she had diabetes, and she was hypoglycaemic the first time that they met, which caused her some embarrassment afterwards.

Joy had worked in a number of non professional caring roles throughout her life, and was currently caring at home for her grandchildren, with whom she had developed a very close relationship. Joy reported that having diabetes was used as an excuse against her by other people in the work situation, rather than by her. The following quotation referred to comments made by a work associate, who Joy felt resented her having diabetes. She reported being made to feel that she was using her diabetes as an excuse to eat earlier than other people doing the same job, when in fact it was being used by others to her detriment. She reported feeling unable to eat when she needed to because of her work colleagues comments, which made her more susceptible to hypoglycaemia.

I don't know why, but she (Work colleague) didn't like me, and she would cause a scene herself. 'She's bringing her diabetes in and she's using it against us', no matter how much you explained.

(Interview data Joy 273-276)

Joy described the trigger for this type of comment being her need to eat. She started work very early in the morning, prior to making the decision to stop work. She needed to go on the first round of breaks to avoid hypoglycaemia, and she was often aware of the early symptoms. She found this attitude to be unfair, as she had been open about having diabetes and her need to eat.

Diabetes as a burden

Claire was concerned that her diabetes did not affect her students' educational experience, as she did not wish to cause undue anxiety, but did want them to be confident in dealing with the situation. She described her diabetes as '*another burden on their shoulders which I feel slightly sad about*' (Interview data Claire 1270–1271).

Claire's perception of diabetes as a burden was in contrast to that of Josie. Claire was concerned about the effect that diabetes would have on others (her students), whereas Josie was more concerned about how it would affect other people's perceptions of her as an individual.

- c) The final theme ***threat to identity*** refers to concepts of fault, vulnerability and secrecy, which were clustered. All of these relate to Josie's perception of herself as a person with diabetes within the workplace. In keeping with the principles of IPA analysis it has been identified as a theme due to the intensity of her feelings in this regard.

However, even when Josie was hypoglycaemic she preferred not to divulge this to others. She either discretely took some glucose tablets, or if the symptoms were very uncomfortable, particularly sweating, she would take glucose tablets, and then leave the

workplace, and dry her clothes with the hand dryer in the ladies lavatory. Reasons that she gave for this behaviour were that she wished to conceal the fact that she was unwell, as she was concerned that her work colleagues' opinions of her would be affected.

You want them to think that you can look after your diabetes, I think that sometimes they may think 'Oh God it must be her own fault she's got one of these hypos' so you just.., I suppose you put on this act that everything's hunky dory.

(Interview data Josie 286–290)

This section has discussed the subthemes identified from analysis in relation to work and study related issues in relation to the major theme of diabetes in everyday life. The next section examines the subtheme of relationships within diabetes in general.

5.2.2 Relationships

The women interviewed were involved in a variety of relationships with partners, children, other dependants, work colleagues, family members, friends and social acquaintances.

The identified clustered themes of the *relationship* subtheme are illustrated in Figure 5.3 and are *family members*, *relationships within the workplace*, and *health care professionals*. Social acquaintances have not been identified as a constituent theme as the data did not suggest they were an issue for this group of women. Relationships within the workplace have been discussed within the previous section. This section will therefore concentrate on the subthemes of: a) family members and b) health care professionals.

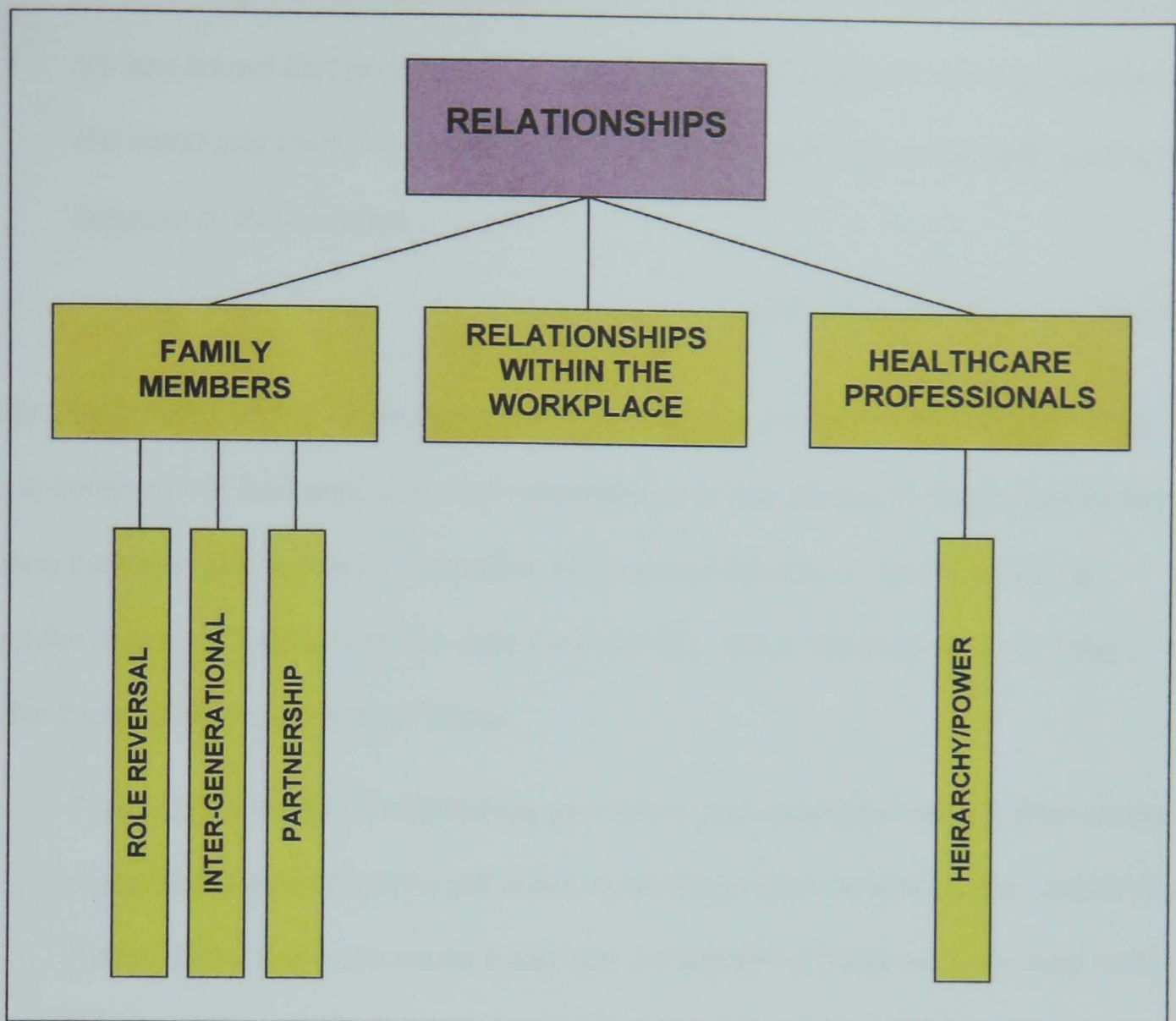


Figure 5.3 Subthemes of relationship issues

- a) The subtheme of ***family members*** relates to role reversal and family members with diabetes in relation to intergenerational and partnership issues.

Role reversal refers to when the woman does not engage in the adult role she normally adopts in her daily life within a social context. Rather than acting as the parent to her children, they may take on a parenting role for her, thereby changing the role of the woman within the family unit. One particular example is that of Paula, who focused on her husband and children. She suggested that worrying about her teenage children becoming more independent as young adults affected her diabetes. Following arguments, her blood glucose levels had a tendency to rise. Her children also had a tendency to worry about her in terms of her overall health and life expectancy.

I think it might be something that'll worry them a bit when we're older, because my son knows that probably when he's working, he might be working anywhere in the world and then he's always going to have the worry of me possibly getting ill because of the diabetes.

(Interview data Paula 1275–1279)

Carla also focused on her relationships with her children. Although she still lived in the same house as her husband, they were separated and she attributed this in part to her having diabetes. She worked in a number of roles and described herself as having a '*peculiar mosaic of jobs*' (Interview data Carla 41-42), which encompassed her roles within the workplace and also at home.

I was very tired and I was fed up, you know, and mealtimes were a little bit more complicated and I think he got even more fed up than he was before, but as I say I don't think it was the cause it just was an additional thing, well our lives were going apart.

(Interview data Carla 92–96)

In contrast to Paula, Carla described diabetes as having a positive impact upon her children's lives as they had learnt to live with the diabetes, rather than struggling against it. They were able to deal with emergency situations, and were aware of the wider implications such as driving and insurance difficulties. They were also aware of the potential for complications and the potential outcome if she chose to misuse her insulin. She described diabetes as putting them on '*an equal footing*' (Interview data Carla 261) and their relationship being more '*reciprocal*' (Interview data Carla 357).

Intergenerational issues were of relevance to Judith as she described how her diabetes interacted with the important people in her life. She ranked them in the following order of priority: her daughter, parents, friends and employer. She described the impact upon her diabetes resulting from any stress with one, or a combination, of these people.

She also described diabetes as impacting upon her relationships with other people, an example being her parents referring to her diabetes as '*her problem*' (Interview data Judith1058), rather than her diabetes, which she found to be an irritation.

He'll (father in law) say 'with your problems should you be eating that?

(Interview data Judith (Interview data 1054–1058)

Lynn focused on relationships with other members of her family, some of whom also had diabetes, including her parents. Her father had had diabetes for some time, whereas her mother had been diagnosed more recently. She found it helpful that her father had diabetes as it had enabled her to recognise the symptoms of abnormal blood glucose levels. The relationship had become more reciprocal since she had been diagnosed with diabetes, as she was able to understand more about his condition, and to remind him about diabetes issues as he got older. Prior to going onto insulin, their relationship had been more volatile with an increased number of arguments, as they did not have a shared experience with regard to oral hypoglycaemic therapy. They both reacted differently to the tablets, which would affect both of their blood glucose levels, although she did say that she had a more modern (flexible) approach to care of her diabetes than him. Both Lynn's and her parents' blood glucose levels were adversely affected by the relationship when there was an element of conflict present.

When I told him I wasn't taking it any more, he'd say 'well you have to, you've got to' and I turn round and say 'sorry, you're not a doctor'. 'But I'm all right,', you know, but 'you're not a doctor', so it would end up where he was getting annoyed, I was getting annoyed, and then his blood and mine would both be, sort of, sky high, because we'd both got into a heated battle.

(Interview data Lynn 841–847)

Several of Lynn's relatives offered unsolicited advice to her, particularly in relation to her eating pattern. '*Panic*' (Interview data Lynn 865 and 984) was a term also used when

referring to her mother and husband, who did not have diabetes, and constantly checked up on her by telephone during the day, an example of infantilization. She felt that her having diabetes impacted upon her husband, as he sometimes felt the need to remind her to eat, as he worried about hypoglycaemia. Lynn reported finding her mother's over protectiveness difficult to handle, and her chosen strategy was to reassure her, whether it was true or not, as the alternative was to get annoyed which would affect her blood glucose level. She also found it difficult to reconcile the fact that her mother was constantly telling her to eat when she was overweight.

When we went out for the day, I phoned her up at the station to say we were coming home, in case she phoned me at home and she'd say 'well did you take sandwiches, have you had something?'. I said 'yeah, we had something in a café'. 'Are you sure?' 'Yes, I've had something; I'll bring you the receipt home if you want'. And then I get annoyed, you know, because she's panicking about whether I've had something or not, so it's easier to agree because I start getting annoyed then.

(Interview data Lynn 878–885)

The reports of both Judith and Lynn in relation to their parents represented an inappropriate interaction between a parent and an adult offspring, and reverted to an adult – child relationship. Infantilization was demonstrated, with manifestations of anxiety and over protectiveness.

Several women verbalised partnership issues with their husbands in relation to daily life with diabetes. Carol described the interaction between her relationship with her husband and her diabetes. If things were not going well between them, her response was to overeat, which in turn affected her diabetes. Although she describes him as worrying about her, there was a contradiction as he did not ring her when he was away, and only took an interest in her diabetes when he was forced to do so. When the immediate

situation was over, she described him '*pushing it to the back of his mind*' (Interview data Carol 1481–1482).

I tend to have worse hypos at night because I don't wake up, you know, and it doesn't make him want to ring or anything.

(Interview data Carol 1428–1431)

In terms of the diabetes he just doesn't want to know. He really does not want to know. And what he does know he's had to know because he's been the only one around who could do anything.

(Interview data Carol 1439–1442)

As she had had diabetes for forty seven years from childhood, and her husband was aware of it when they married, she suspected that he would rather that she did not have it. One of the symptoms of a high blood glucose is the occurrence of vaginal thrush and cystitis, and she described this as '*not having helped our sex life much*' (Interview data Carol 1545–1546).

Marge had also had diabetes since childhood for forty six years and agreed that having diabetes had impacted upon her relationship with her husband to whom she had been married for many years. She had also had diabetes when they met, and she felt that he was still unable to cope with it, except in an emergency situation. The difference between her experience and Carol's was that Marge's husband '*went off the deep end*' (Interview data Marge 706) if she attempted to discuss it with him, and she did not wish him to know that I was researching her experience of diabetes. However, she did feel that he was affected in a positive way as he ate regular meals when she did.

In contrast, Tanya had been diagnosed with diabetes three years previously. She also referred to the fact that her husband did not like to discuss diabetes with her or indeed for her to discuss it. Unlike Marge and Carol's husbands, he did not cope well in an emergency and did not wish to learn more. He preferred her to carry on with life as

normal. She felt that her role as the mother in the house affected everyone, as she defined the mood of the family. In her view if her diabetes was not well controlled and she felt tired and ill, everyone in the family had the potential to be affected. She described not wanting the family to be burdened by her diabetes as it was hers, and not theirs. She also described not wanting to be a victim, as it would affect others in the household, if she allowed diabetes to control her life.

I think, you know you can be a victim, you can enjoy that kind of 'oh everyone will feel sorry for me now because I've got that or whatever you've got' and really make a meal of it. 'Oh no we can't do that because I've got diabetes, so we'll have to do this because ...' I don't like to, I mean I will, if I really have to I will, but you know I don't want to, I'm not really a victim anyway. I think that's a kind of personality that you can have, but maybe I just identify with that because I could be like that so I don't want to be like that, so .., or even a martyr to it really. You know, it can fill a role in your life, you know, you could start manipulating everybody with it.

(Interview data Tanya 993–1093)

However, Tanya also stated that being diagnosed with diabetes had allowed her and her husband an opportunity to reflect upon their relationship, in relation to other major events (particularly the stillbirth of their son) in a positive way. She had also challenged the diabetes, by undertaking long haul travel and sporting activities that she would not have considered doing before being diagnosed with diabetes.

Joanne also described her husband as often taking responsibility for her, and looking after her if necessary, but saw that as a stress in itself as he '*overworried*' (Interview data Joanne 180) about her, and made her feel less confident in managing alone if he was away.

The above illustrations in relation to partnerships demonstrated that the husbands of these women dealt with their diabetes in an inconsistent and ambivalent way. They either appeared concerned or ignored it, with the result that the women reported either feeling ignored or over managed.

- b) The theme of ***health care professionals*** is related to the concepts of hierarchy and power. Judith described her interaction with health care professionals, again demonstrating the concept of infantilization.

They (doctors) make me feel like a naughty little schoolgirl who's not doing things their way. You get 'tut tut tut', because you bring a bag of crisps out to eat because you're hungry. 'Should we be eating those?' Oh it's so condescending.

(Interview data Judith 1107–1110)

Judith's diabetes had been treated with insulin for seventeen years and she reported many occasions where she had successfully managed situations independently. However she also described some of her interactions with health care professionals who she found to be paternalistic and infantilising, if she was not living her life in an ideal way, as defined by health care professionals.

Like many other women in this study, the relationships Carla described with health care professionals were on a much less equal basis. She described the health care system as '*paternalistic*' (Interview data Carla 672). When she first developed the symptoms of diabetes, she correctly diagnosed the condition herself, but was told by a doctor that she had misdiagnosed herself. She asked to do her own blood glucose monitoring, but was given urine testing equipment. Prior to commencing insulin, she asked to increase her oral hypoglycaemic dosage as her levels were still high, but was told (incorrectly) that everything was normal. She described feeling forced to take matters into her own hands, and she independently contacted the diabetes nurses at the local hospital. The outcome was that she changed her GP, but had to wait two years before commencing insulin therapy. She also found the outpatient appointment system at the hospital difficult to

negotiate, as she was given appointments at times when it was difficult to take time out of her work situation. When she was unable to negotiate, she withdrew from the hospital system altogether. She had been diagnosed with diabetes eleven years prior to being interviewed, and had been taking insulin for seven years, and had very little contact with the health care system during this time.

So you begin to see limitations and you suddenly feel you have to become more of an expert, but you mustn't let on. You must learn how to play them, to get what you feel's right for yourself.

(Interview data Carla723–726)

Carmen also focussed on relationships with health care professionals. Like Carla, she had an idea that she had diabetes before seeking medical advice, but this was dismissed by a health care professional twenty years prior to being interviewed for this study.

She was referred to the diabetes clinic at the local hospital, but found a five hour wait excessive and transferred to a private health care provider. One of the advantages that Carmen described was that she had seen the same senior person for eight years, rather than seeing new people every few months at the diabetes clinic, and she was given the required amount of time, rather than feeling rushed through the system. Carmen reported having little faith in her GP whom she felt did not have the relevant expertise in relation to diabetes.

So I went to the Dr and said 'I've got diabetes' and of course she looked at me and said ' rubbish. How do you know that?' And I said ' well, there's this this and this...' 'Well, OK. I'll do a test, but I'm sure you haven't' and of course she did a test and it came back positive.

(Interview data Carmen 316–321)

This section has discussed the impact of relationships upon the women's experience of living with diabetes. Although in psychosocial terms the women were engaged in

relationships within an adult context and taking an adult role, this was at times reversed in relation to the management of their diabetes, particularly by family members and health care professionals, with responsibility being removed from the woman herself. This encourages the woman to adopt a less active role in the management of her own care, and can be viewed as disempowering. The following section examines the subtheme of *social activities* before the final section of this chapter considers the subtheme of the roles that women undertake in everyday life.

5.2.3 Social activities

As well as their roles in the workplace and the home, many of the women in this study were involved in a variety of social activities, ranging from hobbies to socialising with friends. Diabetes was reported as having impacted upon these social activities, and there was also the potential for social activities to impact upon the women's diabetes. Social activities which involved eating and the avoidance of hypoglycaemia were reported in this way, and have been singled out as this was the most common aspect of social activity that was discussed.

Angela described eating out as being problematic and she described feeling in a quandary as to whether to eat before she left or to wait until the event, and risk becoming hypoglycaemic. Timing of blood glucose testing could be problematic if she was unsure of the duration of the meal, or if it was particularly prolonged. If there was insufficient carbohydrate within the meal, embarrassment could result if she needed to eat extra, which she tried to do surreptitiously. She also found shopping stressful, as it took longer, as she checked labels for the amount of sugar and carbohydrates. She referred to the problems related to shopping and eating out as being:

Surmountable, you can overcome them, but they are little niggling somethings that worry, or the other thing is that you leave your insulin where you've been and come home without it, which can be annoying.

(Interview data Angela 36–39)

Joanne referred to an incident that occurred during a coach trip as being embarrassing, as she did not know many of the other people well, and they were unaware of her having diabetes, which she had had for thirty eight years.. She was out for the day, and due to the organisation of the day, was not able to stop for coffee and lunch until three o'clock in the afternoon.

So it made it very difficult, and I didn't feel like I could go up and say 'look you have got to reorganise the whole thing because of me.' Luckily I am always the sort of person who is prepared and takes things with me, so I managed. I was doing blood tests and having bits and pieces to eat. Then when it came to the meal obviously I didn't really enjoy it because I wasn't hungry. So I ate the meat and vegetables and left the rest.

(Interview data Joanne 162–171)

Claire also described her embarrassment at being hypoglycaemic at a social event. Her journal entry has been included in its entirety.

11th October (Breakfast)

Dear J

Strange night – last night. Went to jazz concert to see friend's band. I felt 'strange' during the performance and my friend 'dealt' with me. When I recovered – a woman from the audience came over and complained about the noise from our table. I think it's the first time I have felt discriminated against. At the interval

my friend went up to the complainer and put her right! The next thing was a big discussion about diabetes etc. My friend phoned me this morning and she was quite upset by the incident.

A good jazz concert however.

C

This section has illustrated the single theme of *eating and avoidance of hypoglycaemia*. Data analysis has demonstrated that there is both the need for planning and structure, and the requirement for the woman to take responsibility for her own food intake. However, the women’s reports in this chapter have indicated that even with meticulous planning on the part of the woman, there is always a degree of uncertainty and hypoglycaemia may still occur. This can result in a loss of both glycaemic and psychological control as will be discussed in Chapter 7. A common thread of embarrassment has been highlighted throughout the women’s accounts. The final section in this chapter is concerned with the roles that the women undertook in their daily lives.

5.2.4 Roles in daily life

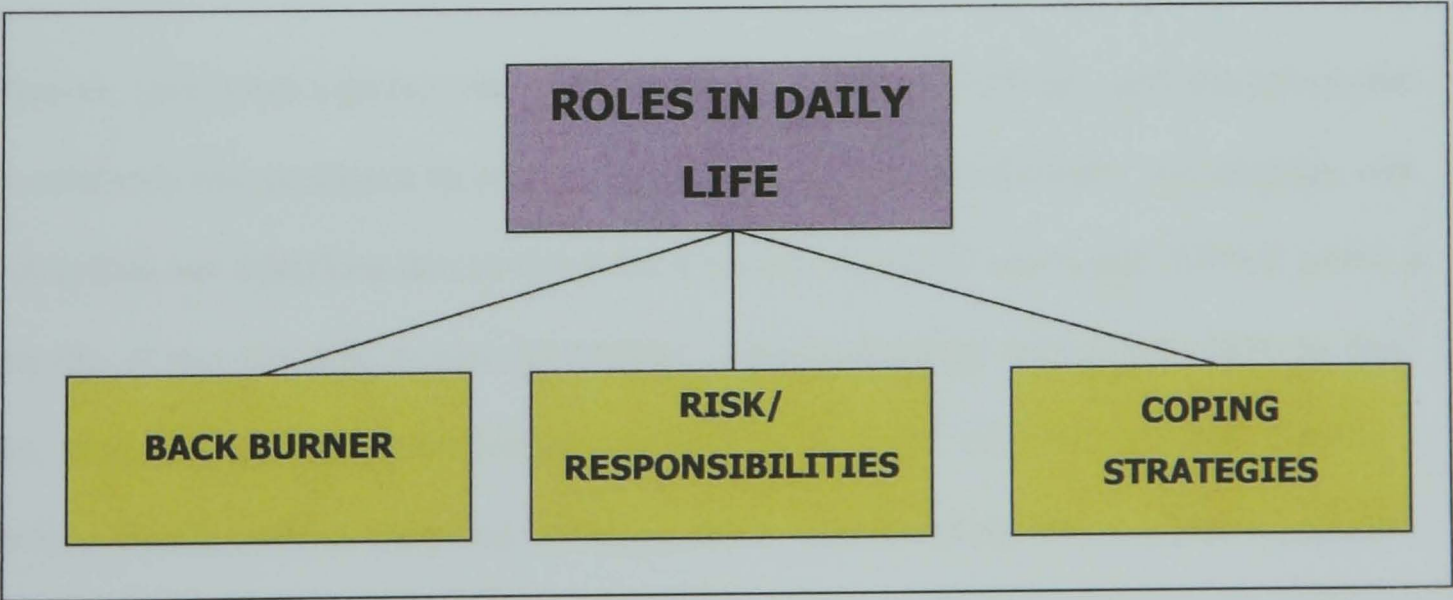


Figure 5.4 Constituent subthemes of roles in daily life.

The identified clustered themes of the *roles in daily life* subtheme are a) the back burner, b) responsibilities and risk and c) coping strategies.

Some women described a high volume of roles in everyday life – in the workplace, home and socially and demonstrated an ability to multi-task. They reported a range of perceptions both with regard to how their diabetes impacted upon these roles as well as how diabetes itself was impacted upon by these roles.

- a) The theme, ***the back burner***, refers to giving issues other than diabetes a higher priority. Irene fulfilled a number of roles in a busy life, in which she had had diabetes for forty seven years. She was a wife, mother, and daughter with a caring responsibility for her mother; part time employee and church member. All these roles had meant that diabetes in itself did not take priority in her life. She referred to a particularly busy period in her life, when she was working and had young children.

I was just always in a hurry and I never had time to think about it, and I used to get told off for not testing myself more and things like that. The thing is I didn't give it a high priority.

(Interview data Irene 1880–1884)

However, giving her injection had always been a high priority for her, and she attributed her relatively few problems to luck, rather than her good management. Her strategy was to prioritise her injections and to eat small amounts regularly, which was difficult within a busy life. If she was able to plan for the day in advance things were much easier to deal with, than having to deal with unexpected events. However, at times diabetes came to the fore if sufficient planning had not taken place. She found spontaneity a difficulty. In her role as a wife, she gave an example of her husband wanting to stay on when they were away somewhere, and she was unable to do so because she needed more insulin supplies, or there were problems if she had forgotten something.

We went out for a long day, and I forgot my injection. We got right out to the coast, and I realised I'd forgotten them. I'd forgotten to do my morning injection, called in to a Dr's surgery and they wouldn't give me any insulin. Well I just had to survive the whole day, just drinking and drinking, and not eating anything, and got back at night, but it just seemed to me so crazy, but they wouldn't

(Interview data Irene 33–37)

- b) In the context of this section, **risk and responsibility**, relates to issues which may be taken for granted by women who do not have diabetes, but pose an element of risk to those who do. Undertaking many roles in daily life required the women to drive, which is not always straightforward for people with diabetes. Lesley was concerned with the injustice and prejudice around diabetes in terms of insurance, both motor and life, as she had found that policies were more expensive because she had diabetes for the twenty years since diagnosis. She was aware of the consequences of hypoglycaemia when driving. Her strategy was to ensure that she always had carbohydrate readily available (except when the children ate it!). She was able to recognise warning signs and would pull over. However, she did not always have blood glucose testing equipment with her.

Stopping driving had become a reality for Pam since commencing insulin three years previously, due to her failing vision which she attributed to diabetes. She suffered from blurred vision, which may have been due to a high blood glucose level, rather than long term complications, but she described how her concentration was affected. She had not driven for several years prior to the interview. In addition to the safety aspects, she wished to avoid any undue stress which could potentially lead to the development of long term complications.

- c) The final theme in this section, **coping strategies**, refers to the steps women took to manage the potential for diabetes related risks within the context of their roles in daily life. Lois described when she was diagnosed fourteen years

previously. She was working and had a three year old child. She had been very unwell prior to this and her weight had fallen to five and a half stone. Her major stress was due to hypoglycaemia which occurred as a result of commencing human insulin. Her job entailed night work at times, and driving several miles. Her way of coping was to keep her blood glucose levels high, to avoid the risk of hypoglycaemia, which worried her as she was aware of the increased potential for the development of irreversible long term complications. She found health care professional advice unhelpful and took matters into her own hands.

Unfortunately didn't see Professor X - I saw his side kick who actually said it was me that wasn't controlling it properly it wasn't the insulin problem because nobody else had any problems. Then the following day I picked up the Times and there was somebody else complaining about exactly the same thing I was complaining about. So I rung up Professor X and made an appointment with him and went out and took all the insulin back.

(Interview data Lois 64–71)

This chapter has examined the themes of work/study issues, relationships, social activities and roles in the context of the major theme of daily life with diabetes. The themes have been examined individually, although it is recognized that there is a degree of interaction and overlap between them. This is particularly pertinent in relation to a desire to avoid the onset of hypoglycaemia. Management of risk and the potential for a change in the perception of the woman by both herself and others run throughout the subthemes due to the unpredictability of diabetes, as her role in society is changed by having diabetes.

The chapter is concluded by consideration of Annette's experience of daily life with diabetes, the complexity of which is demonstrated within her account. Annette's account has been left until last, as it encompasses many of the other women's reported experiences. She had lived with diabetes for thirty six years. When she was asked to describe what she found stressful in her daily life in an isolated rural area, she responded as follows:

Absolutely everything. As I've got older I've become stressed by everything. That's not an exaggeration, it's accurate. Yes, everything. The post coming in the morning, have I forgotten a particular bill? Have I not made allowances for it? Walking down the street. Everything, meeting people, talking to people, even people I know, I just find the whole daily process stressful. I wonder if it's because I'm living in this sort of insular place and I just don't mix often enough to be able to cope with these things any more, I don't know but I am a highly stressed person.

(Interview data Annette 1288–1298)

She describes diabetes as affecting her relationship with her husband and her children, in relation to perceived role reversals and role changes. Her husband had commented that he felt '*more like a carer than a husband*' (Interview data Annette 367) which she described as '*being rather like a verbal slap in the face*' (Interview data Annette 367). In a similar way to Paula's children, her relationship with her children was at times reversed as they took on a parenting role – ringing her to check that all was well, or dealing with her if she was unwell due to diabetes. In her work situations, she was worried about appearing incompetent, particularly if she was having a telephone conversation with someone she did not know, and she would be left feeling embarrassed. She was clearly upset by an incident which occurred during her pregnancy, illustrating the hurtful effect that other people's views about diabetes had upon her.

I once was waiting for a hospital appointment when I was pregnant, and there was an elderly gentleman sitting next to me and he wondered what was wrong with me. I told him. And he said 'My God and you're going to have children? Don't you think that's grossly unfair?' So he formed an opinion about my responsibility to my future children, based on the fact that I had diabetes.

(Interview data Annette 327–333)

Annette's account combines many of the elements in one person that have been demonstrated across the group of women as a whole, and has been reported in keeping with the principles of IPA analysis. Her account encompasses elements of professionalism within the work role, reversal within her relationships with her husband and children, perceptions of her as a person based upon the fact that she had diabetes and the coping strategies she employed in dealing with all of these issues. In this way, she highlighted the complexity of living with diabetes in daily life.

The following chapter is concerned with the impact of diabetes during times of crisis, in contrast to living with diabetes in daily life.

CHAPTER 6

Diabetes at times of crisis

This chapter is concerned with the analysis of data relating to times in the women's lives when the daily course of events was disrupted. Women's descriptions of what they experienced as stressful in relation to their diabetes at these times, and the impact of this stress on their lives has been examined, demonstrating the complexity of the relationship between life and diabetes within interrelated situations and the diversity of events that occurred.

Figure 6.1 illustrates the relationship between the constituent subthemes which were a part of the major theme of diabetes at times of crisis, and with the major theme itself.

Three subthemes were identified from this analysis:

- a) Life events
- b) Physical or psychological health related episodes
- c) A complex situation.

In contrast to Chapter 4, where a more creative poetic representation was adopted as the style of choice to represent data, this chapter reflects a more realist stance as described by Sparkes (2002). However, it is important to note that the interpretations are derived from the women's *perceptions* of the impact upon their diabetes of events that they report, rather than in terms of any statistical causal relationships.

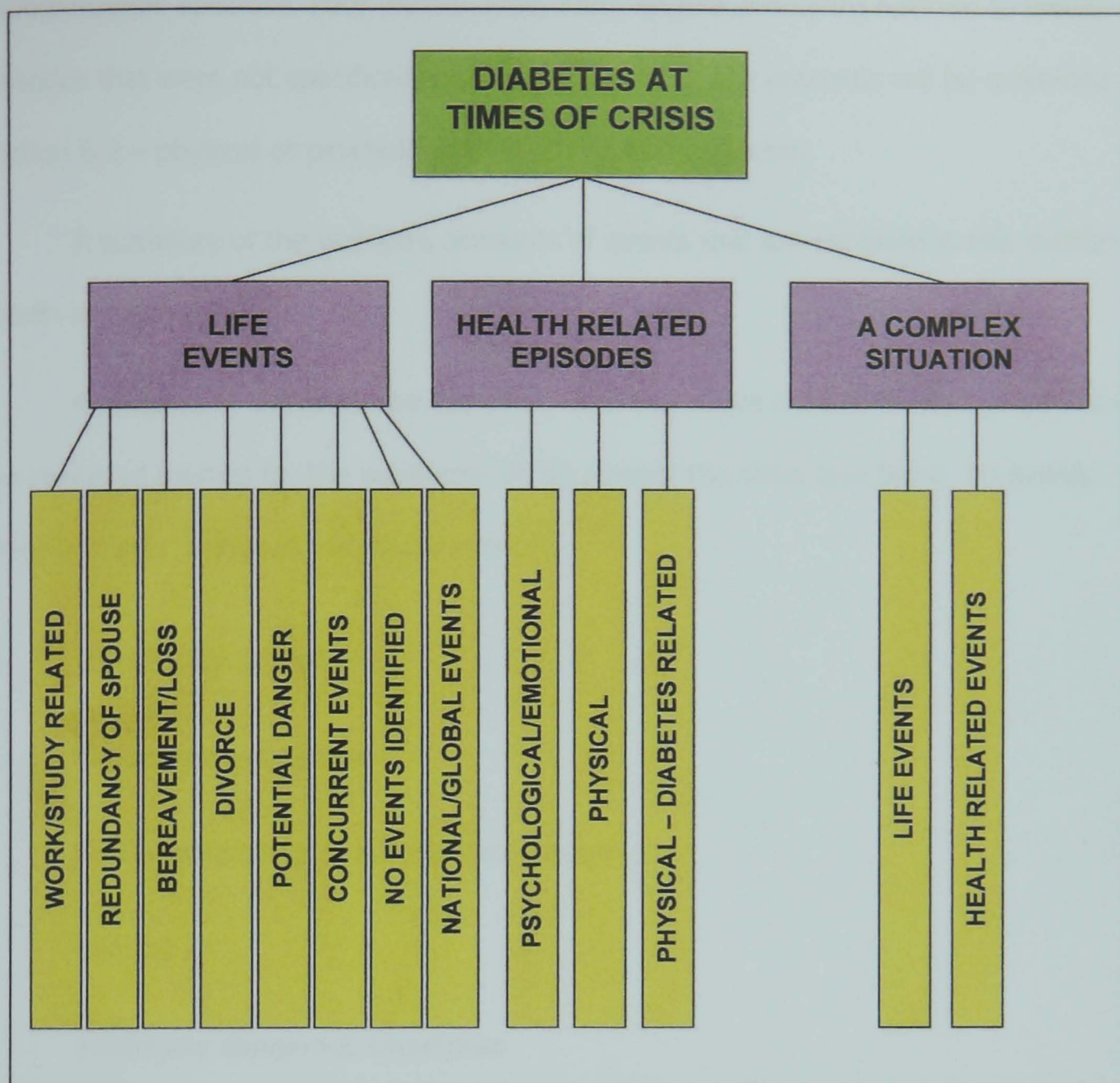


Figure 6.1 *Diabetes at times of crisis.*

All the women except Tanya were able to identify specific events, with Irene and Jane identifying several events occurring concurrently.

6.1 Life events

In this section, life events are those identified by the women interviewed as being the most stressful in their lives since their diabetes was treated with insulin.

Fifteen women's accounts of events have been included in this section. Seven women's accounts have not been included within this chapter for the following reasons. Gina's account will be discussed in the section relating to a complex situation. Although the question was asked in the context of general stress, Claire and Janice both described

hypoglycaemic episodes. Four women (Joy, Pam, Angela and Lynn) referred to medical episodes that were not specifically diabetes- related. These accounts will be examined in Section 6.2 – physical or psychological health related episodes.

A summary of the women’s accounts of events that are explored in this section are shown in Table 6.1¹.

Five types of event can be identified from the above table and constituted five of the clustered themes for the subtheme of life *events*, the other two being '*no events identified*' and '*national and global events*'.

- Work/study related
- Redundancy of spouse
- Bereavement/loss of a close family member
- Divorce
- potentially dangerous situations.

The largest group of women (6) experienced events in relation to work and academic study, followed by redundancy of spouses (4) and bereavement of close family members (4). The least number of women reported events relating to a change in caring responsibilities (2); moving house (1); divorce (1) and being in potentially dangerous situations (1).

¹ In order to avoid confusion, the word impact has been used to signify perceived links between events and diabetes, as reported by the women interviewed. No causal relationship is implied in statistical terms.

Table 6.1 Life events

Name	Event	Perceived impact of event upon diabetes	Perceived impact of diabetes upon event
Carol	Giving up professional work	No	No
Lesley	Work presentations	Unsure	Yes
Josie	Academic assignment	Yes	Unsure
Lois	Husband's redundancy	Yes	No
Carla	Work injury	Yes	No
Irene	<ul style="list-style-type: none">• Father in law moved in• Husband's illness• Son and daughter became mentally ill• Husband made redundant• Irene increased her working pattern to full time instead of part time	No	No
Jane	<ul style="list-style-type: none">• Daughter became mentally ill• Death of father• Moved house• Husband's redundancy• Husband's illness	Yes	Yes
Judith	Divorce	Yes	Yes
Paula	Death of father	Yes	Yes
Joanne	Husband's redundancy	No	No
Joan	Academic exam	Yes	Yes
Marge	Horse jump	No	No
Carmen	Son emigrated	No	No
Mandy	Death of father	Yes	Yes
Annette	Death of daughter and father	Unsure	Yes

The majority of women (8) perceived there to be a connection between the event and diabetes, in that their diabetes was impacted upon by an event. Types of event where a connection between the event and diabetes was perceived related to divorce, bereavement, work or study related, redundancy of spouse and multiple events occurring simultaneously. Two women who had experienced work related events and the death of two family members were unsure whether the event had impacted upon their diabetes. Five women reported that there had been no impact on their diabetes. Where no impact on diabetes was reported the events related to work issues, redundancy of spouse, loss of a close family member, a potentially dangerous situation and multiple events occurring simultaneously. There was therefore no pattern to the type of events experienced and the perceived effect on diabetes, suggesting that it was the individual response of the woman concerned which influenced the perceived effect on diabetes.

In terms of diabetes affecting their experience of the event, equal numbers (7) of women reported that there was a connection, as those perceiving no connection (7). One woman was unsure whether diabetes had impacted upon the event. Five of the women who perceived there to be no connection in terms of diabetes affecting the event were the same as those who perceived their diabetes as not having been affected by the event – Carol, Irene, Joanna, Marge and Carmen.

In summary, the following observations can be made:

- Of the 15 women who reported an event, five women reported no link between the events experienced and diabetes – Carol, Irene, Joanne, Marge and Carmen.
- Five women reported a bi-directional link between events and diabetes – Jane, Judith, Paula, Joan and Mandy.
- Three women were unsure of the existence of a link – 2 whether the event had impacted upon their diabetes (Lesley and Annette) and 1 whether diabetes had impacted upon the event (Josie). Although Lesley and Annette were unsure

whether the event had impacted upon their diabetes, they reported that their diabetes had impacted upon the event. Josie reported that the event had impacted upon her diabetes, but was unsure whether her diabetes had impacted upon the event.

- Two women reported the event having impacted upon diabetes, but that their diabetes had not impacted upon the event – Lois and Carla.

In keeping with IPA analysis, individual women's experiences of each type of event will now be discussed in more depth and contextualised, together with further exploration of the link between diabetes and events in the women's lives. This will be followed by an exploration of the women's concurrent experiences (Irene and Jane), and an interpretation of why Tanya did not identify any events since being treated with insulin. An additional type of event will also be examined, which emerged from examination of journal data following interview – national and global events.

6.1.1 Work and study related events

Six women described events in relation to work or academic study. Within this group of women, Irene's experience was in relation to a number of concurrent events occurring and will be discussed later in this chapter.

Both Josie and Joan identified events relating to their experience of academic study. For Josie this was an assignment for submission, and for Joan an examination. Joan described herself as feeling out of control in the build up period prior to the examination, and described her blood sugars increasing during this time. She attempted to rectify the situation by taking extra insulin, but this was not always effective. She reported that her concentration was impacted upon by her diabetes, which affected her success during the examination. Although Josie's academic progress was assessed by a different method i.e. a written assignment, she found this to be extremely stressful, to the extent that she reported that she suffered panic attacks. Her diabetes was impacted

upon in terms of falling blood glucose levels leading to hypoglycaemia. Attributing an impact upon the event by her diabetes was more difficult, as she was also going through the menopause, which also led to her having difficulty concentrating, and also affected her emotions. This was apparent during the interview when she became upset and began to cry. She explained that her distress was due to not knowing whether these symptoms were due to her diabetes or the menopause. This was difficult for her, and was affecting her relationship with her husband and her confidence in her ability to do her administrative job:

I don't know, I can't really, you know, always blame the diabetes, but knowing that I haven't always been like this, just keep thinking perhaps because it is the menopause coming.

(Josie Interview data 619–622)

Josie also questioned why she continued with something that she was uncomfortable with and disliked (the academic assignment), and concluded that it was not for her own satisfaction. She did not expand upon the notion that she was doing it for some reason other than her own satisfaction, just that it was not for her. I interpreted this as her meaning that she was studying to prove something to other people rather than for her own benefit.

It's doing something I suppose that I don't really want to do. I've given it a try, I don't like it, but no doubt I'll try to finish it. Yeah, but it's as if you put yourself in these positions, for what reason? Not for you.

(Josie Interview data 574–577)

Carol, Carla and Lesley found events in the workplace stressful. Carol had been involved in professional conflict with colleagues. This also translated into personal conflict for her as she reported feeling '*in a no win situation again*' (Carol Interview data 2085) as she felt that she was unable to cope with the situation but was also letting other people down.

She made the decision to leave the job, but then encountered more stress as she was unable to find another suitable position. This was a new experience for her as she had always previously been able to find employment. Although she had reported that diabetes was not linked with the professional episode, this was due to her adopting a particular position to cope with the situation, which was not just denial of the situation, but a positive decision to ignore her diabetes which she called '*purposeful blindness*' (Carol Interview data 2159). However, she did not specify how she ignored her diabetes at times, which had the potential to be detrimental to her condition. She described it as follows:

Yes, I've never been able to label it myself as denial, because I've always known I was diabetic, I've always taken my shot. I've, you know, how can you deny something that you have to take an injection for twice a day, but at the same time, certainly there were large parts of diabetic management that I simply was not admitting applied to me, you know.

(Carol Interview data 2146–2152)

Carla, in a similar profession, had suffered an injury at work, which was inflicted by someone else when a challenging situation had got out of hand. Her diabetes had been affected, in that her blood sugars had risen, and she understood this to be partly due to the effects of adrenaline. Her response to the question as to whether diabetes had impacted upon the situation was '*I prefer not to think so*' (Carla Interview data 1016), suggesting an element of doubt in her mind.

For Lesley, giving presentations at work was a major source of stress, as she did not like to be in the spotlight, preferring more informal methods of communication. She preferred to take complete responsibility for her work, finding it even more difficult if she was in a situation where she had to rely on other people's notes, rather than having time to prepare her own, a principle which she also applied to management of her diabetes – she liked to be in control. She was unsure whether her diabetes was affected by giving

presentations as she did not carry out a blood test at the time, but she suspected that her blood sugar dropped as she had symptoms of hypoglycaemia. Her diabetes also had the potential to disrupt her presentations if they ran through a meal time, and she had been forced to interrupt the session to eat to avoid hypoglycaemia. Although she described presentations as being a major source of stress, she did not necessarily view this as a negative thing, viewing them as being *'probably the stress that makes you perform rather than inhibit you'* (Interview data Lesley 588–589).

6.1.2 Redundancy of spouse

Four women identified their husband's redundancy as a major episode in their lives. Two women (Irene and Jane) referred to this in the context of concurrent events, and their experiences will be discussed later in the chapter.

Lois and Joanne were the other two women who referred to the redundancy of their spouse, but only Lois reported this as impacting upon her diabetes. Lois' husband was made redundant at the age 57, having planned to retire at 60. This had major financial implications as both Lois and Joanne were told there would be no pension and they had two children in full time education. Lois was already working full time. This event impacted upon her diabetes in that her blood sugars rose, which she felt left her more open to infection², which in turn took longer to get better. She reported the rise in blood glucose as being the result of stress and also that stress affected the way that she managed her diabetes:

If I'm really stressed out then I will cheat on my diet. Then I pay the price because my blood sugar goes up and then I feel sick and I think 'what a stupid thing to do why did I do that?

(Interview data Lois 1238–1241)

² The rate of infection is higher in people with diabetes than those in the general population, due to compromised immunity, and hyperglycaemia may delay wound healing.

In spite of the severity of the situation, she was able to see a positive side, in that the redundancy happened during the winter, as she became hypoglycaemic during hot weather which had the potential to cause problems. Diabetes did not impact upon the redundancy, as it took second place to her husband's needs, as she demonstrates below. This could be interpreted as the redundancy taking the focus away from the organisation of the structure of diabetes management.

I think that (diabetes) just paled into insignificance to be honest. He got so low and so depressed that sort of he was the focus of everything.

(Interview data Lois 118–120)

Unlike Lois, Joanne was not in full time paid employment. However, it was not the financial aspects of the situation that concerned her, but the emotional effect upon her husband, similar to the concerns voiced above by Lois. The situation was made worse by the fact that it took a year for her husband to become re-employed. However, she was definite that her diabetes was not affected by or affected the redundancy, and her experience differed from that of Lois in this respect.

6.1.3 Bereavement/loss of a close family member

Four women referred to family bereavements as a source of stress, which they all perceived to impact upon their diabetes – Jane, Paula, Mandy and Annette. Jane's experience will be described later, in the context of concurrent events. All four women referred to the death of their father, and Annette also to that of her daughter. Carmen also referred to her son emigrating, and this has also been included in this section, as a loss is often viewed in terms of a grief reaction, similar to that of bereavement.

Paula was clearly emotionally upset as she talked about the death of her father during the interview. He also had diabetes, but his death was unrelated to this. During the time of his dying, her own diabetes control was impacted upon as her blood sugars were erratic, as she did not test as frequently as usual as diabetes took second place,

testing only at home and not at the hospital when she visited her father for prolonged periods of time. She described her diabetes as *'it wasn't something I was too worried about'* (Interview data Paula 328–329). She reported that her diabetes did impact upon her (and others) experience of her father's death. Other family members did not have a break, but she was able to leave at regular intervals in order to eat, as well as to look after her children and to have a break.

I didn't get the worst of it because I wasn't one of the ones that were there the whole time. From my point of view it was a break, coming away.

(Interview data Paula 350–352)

She also stated that coming away from the hospital was out of concern for her mother, who she thought would worry about her if she did not go and eat. This may have been a way of her meeting her own needs, without requiring her to be open about them.

In contrast to the prolonged illness of Paula's father, Mandy's father died suddenly, when her son was nearly a year old. She also took responsibility for her mother at the time, as well as herself and her baby. She reported that she had no support from a partner, and reported an impact on her diabetes in terms of erratic blood glucose levels. She attributed this to a lack of time available to spend managing it, and also the physiological effects of grief and stress. She felt that diabetes impacted upon her experience as it added to her already considerable difficulties. She had no warnings of hypoglycaemia, and became hypoglycaemic on the day of the funeral.

Annette stayed at the hospital with her father during his terminal illness. She describes deliberately keeping her blood sugars high to avoid becoming hypoglycaemic, as she wanted to be available if he needed her. This is an example of a woman with diabetes putting the needs of her diabetes second to the needs of someone else:

I deliberately kept my diabetes on the high side, so that I wouldn't go hypo and mess up. I couldn't take the risk, so I did purposefully keep my diabetes on the

high side in that situation. I remember that, so that was a deliberate act and I think it was the dreadful situation that caused me to do that though, it wasn't my diabetes causing anything, any of the stress. It was to reduce the stress my diabetes might cause if I didn't do that.

(Interview data Annette 1272–1280)

In addition to the death of her father, Annette recounted her experience of her ten year old daughter's death. This was described in more graphic language, as Annette's words demonstrate, and she described the profound physical and emotional effect this had upon her:

We got there and she had died at twenty past four, and it was just the most awful thing – nothing can beat it on a scale of awfulness. The reaction to it, the first reaction, the initial reaction was a feeling of complete nausea, neither of us were actually sick, but well, I felt as though I wanted to be sick and shaking and hot and cold. The physical reaction was extreme, but the stress reaction carried on for months after that.

(Interview data Annette1208–1215)

Her daughter had a congenital condition and had been in hospital for several days, after being unwell for some time. Annette and her husband had returned home to care for their other children and to attend to their work as they were both self employed. Their daughter deteriorated unexpectedly, and had already died by the time they reached the hospital, some three hours away from their home, in spite of the fact that they returned as soon as they were contacted. Annette describes the intense guilt and lack of control she felt at the time.

I think parents expect to die first; its standard behaviour isn't it? And as a parent I'd always felt entirely responsible for my child – how happy my child was, how healthy my child was, it was my responsibility, and my child was dying, I had

failed as a parent, it was horrendous and of course my major thought was, 'what sort of a mother am I? I'm not there with her'. I had this image that I could actually stand there and scream at her, 'come round. You can't die' and she would have. That was the image I had, it was awful and we had a three hour journey.

(Interview data Annette1196–1205)

Annette could not remember whether there was a link between her daughter dying and her own diabetes, as there were so many other things taking priority, and her normal pattern of life was completely disrupted. This suggests that, for Annette, the higher intensity of an event, the greater the degree of impact upon her diabetes. Whereas she had previously referred to deliberate manipulation of her diabetes in relation to the death of her father, the reaction in response to the death of her daughter was an involuntary one, as she describes in relation to her physical response on the previous page.

Although Carmen described the emigration of her son as being the single most stressful event that had happened since her diabetes had been treated with insulin, she did initially question whether stress was the right word to use, although later described it as being a stressful time. Carmen's *Living with Diabetes Questionnaire (LWDQ)* responses also indicated that she did not view diabetes as impacting upon her daily life and work, and that she did not find living with diabetes stressful. Her positive response to survey questions identifying that stress affected her diabetes and the way that she managed her diabetes, were contradicted in this instance, as she stated that *'I don't really think there's really any correlation between the two'* (Interview data Carmen 766–767), and she continued with her daily activities as usual.

6.1.4 Divorce

Only one woman referred to divorce as a time of crisis resulting in disruption and change. Judith described her divorce and its subsequent implications as the most stressful episode that had occurred since her diabetes was treated with insulin. She became a single parent

to a teenage daughter who was also experiencing difficulties in general. Judith also reported subsequent issues related to financial difficulties and the worry of losing her house, police involvement with her husband's behaviour, increased alcohol consumption to enable her to sleep, and a lack of self esteem and trust. Although she had increased alcohol consumption, she stated that this only occurred late at night when she was sure that her daughter was settled, still giving her role as a mother priority in difficult circumstances. The effect of the divorce was ongoing, as financial problems were still affecting both her and her daughter at the time of the interview, as she found it difficult to meet her daughter's financial wants, which had a negative effect on their relationship. She reported that her diabetes was impacted upon in different ways in both the short and the long term. In the immediate period surrounding her divorce she was admitted to hospital with hypoglycaemia which she believed was linked to her alcohol consumption. In the long term her glycaemic control improved as she was experiencing less sustained stress after her husband had left, which she saw as having a major effect on her diabetes control. Having diabetes had also impacted upon the divorce process, as she stated that her husband had used it in the court case in relation to her losing her temper.

6.1.5 Potentially dangerous situations

Only one woman referred to a potentially dangerous situation, where her personal safety was at risk. Horses played a large part in Marge's life and daily routine, as was apparent in her home and land. She recounted undertaking a horse jump in a difficult, and potentially dangerous, situation. She described the experience as '*I think probably the most terrifying thing I have ever done*' (Interview data Marge 1267–1269). She believed that her diabetes was not impacted upon as there was no build up to the situation and that the episode was not impacted upon by her diabetes as it took place between meals when her blood sugar was stable. Her everyday roles and relationships were unaffected. Although there is no evidence of her diabetes being affected, this account has been included, as she referred to the horse jump as being the single most stressful thing in her

life since being diagnosed with diabetes. Omitting this account would have left her the only woman whose account was not included in this section, the exclusivity of which does not accord with the feminist philosophy of the study. It is possible that her diabetes was not affected due to the very short term effect of the stress experienced and its immediate resolution.

The previous sections (6.1.1–6.1.5) have discussed women's experiences of individual events. However, both Irene and Jane described a number of events that occurred within a short space of time, and for this reason they have been considered together, rather than as single events as described above, as it was difficult to separate them. A specific time period within which several events occurred has not been defined, as it is the women's perceptions of their concurrent nature that were considered.

6.1.6 Concurrent events

Jane described the events that she experienced as occurring within a year, and Irene did not specify a time period, but referred to the events occurring '*at the same time*' (Interview data Irene 2435) and '*they came together*' (Interview data Irene 2449). Both women experienced a change in caring responsibilities as Irene's father in law moved into the family home and both had children who developed mental health problems. Both also had husbands who were made redundant (twice in Irene's case) and became unwell. In addition Jane experienced the death of her father and also moved house, and Irene changed her working pattern to full time from part time.

In spite of the similarities between some of the events in terms of relating to time and focus, both described very different views in terms of the links between diabetes and the times of crisis.

Irene perceived that there was no direct connection between the events she reported and her diabetes, and offered two potential reasons – lack of time and control of the situation, and the fact that she had been diagnosed during childhood, having had

diabetes for more than forty years. She describes a consultation with health care professional to illustrate the first point:

I mean I didn't keep very good control, I really didn't , and I was told off when I went to diabetic clinic and I used to say to them, 'but I haven't got time to think about it, I just haven't got time', and then they'd tell me off about that, and I thought 'well you try'.

(Interview data Irene 2482–2487)

However, this excerpt suggests that her diabetes control was poor and that events may well have had an impact on her diabetes; which she is actually alluding to in her comments about not having the time to look after her diabetes. In terms of her diabetes in general she says *'I didn't take it that seriously and I never had any obvious signs'* (Interview data Irene 2548–2549). However, in a later communication following the interview she wrote that she had had extensive cardiac surgery, due to cardiovascular complications of diabetes. In terms of the contradictions in her responses, it could be argued that this is another case of *'purposeful blindness'* previously described by Carol in Section 6.1.1. Irene also described how she could always make sure that her blood glucose test was *'absolutely spot on'* (Interview data Irene 112) before the advent of glycosylated haemoglobin screening, by manipulating her insulin and food intake, suggesting she was purposefully blind to her true results, and also had the potential to affect the professional judgements of health care professionals. Both Carol and Irene had been diagnosed with diabetes during childhood, and may have developed this strategy over a prolonged period of time.

Irene went on to describe how she felt that diabetes had become part of her as a person and a way of life.

If you've got a chronic illness, it's so much part of your whole persona isn't it? And your personality and everything. I often think that. Acute illnesses are quite

different. They're external and you get rid of them, but a chronic illness is somehow internalised, and it's the whole of you.

(Interview data Irene 2562–2566)

In contrast Jane described how her diabetes had been impacted upon by stress, and went so far as to say that having diabetes gave her a potential escape route from her social situation, indicating the severity of the stress she was experiencing and suggesting an imbalance in both the psychosocial control of her life and also her diabetes control.

Well as far as the diabetes was concerned that just completely went out of the window, so that the blood sugars were just up and down like a yo- yo, and then I just couldn't be bothered to do anything about it, I just, I mean it got to the stage at one point where I didn't even take my injections, I think that's the only time in 20 odd years that I had stopped taking my injections and of course that made me really ill, which it didn't help, but that was all tied up with the stress really, I think anyway.

(Interview data Jane 1011–1019)

She also viewed diabetes as impacting upon her experience and ability to cope with the times of crisis, and indirectly her perception of the events themselves, as it exaggerated all of the other problems. She refers to her views on the relationship between stress and diabetes in her journal entry, and the fact that her diabetes control did not improve in spite of her efforts to rectify it:

Stress certainly affects blood glucose – been in or just below 20s all day. Makes me feel rotten, I've had a bit extra in the insulin dose but it doesn't seem to make much difference. It's at times like this when I wish I wasn't diabetic.

(Journal data Jane 12th September)

This section has been concerned with women's perceptions of life events, and the connections between these events and diabetes. However, one woman did not identify any such events as discussed below.

6.1.7 No events identified

Tanya was the only woman who did not identify a time of crisis since her diabetes had been treated with insulin. This may have been for two reasons. Of all the women interviewed she had been diagnosed with diabetes for the least amount of time – three years at the time of interview. She stated that she was probably more stressed before the diagnosis, when she had suffered a stillbirth and had thought that she had cancer, hence having diabetes had come somewhat as a relief. She clearly had mixed feelings about having diabetes and identified it as a catalyst for re-evaluating her life:

Diabetes is my friend, enemy, support and teacher and boy some things I'm not sure I really want to learn about much less actually think about and do something.

(Journal data 19th August 2001 Tanya)

All of the events which the women referred to during the interviews were related to their personal circumstances. Although none of the women referred to national or global events during their interviews, four women made reference to them in their journals, and these are discussed below. There were no obvious similarities between the four women.

6.1.8 National and global events

Joy referred to a spate of child disappearances and murders, both in the UK and in Europe, but did not relate it to her own experience. Tanya, Paula and Carol both referred to the terrorist attacks on the twin towers. Tanya writes that *'it feels like it will never be the same again'* (Journal entry Tanya 11th September 2001), and her thoughts on how her philosophy of life had been affected:

Live every day to the full, tell everyone your feelings for them on a daily basis and pray for that as mankind we may learn to live peacefully with each other.

(Journal entry Tanya 11th September 2001)

Paula describes the impact upon her blood sugar after hearing the news and her concerns for her family:

Sugar rose to 18 after hearing from son that after the terrorist attacks in America Canary Wharf was being evacuated and tubes would be disrupted.

(Journal data Paula 11th September 2001)

I'm now a nervous wreck about both my children being in major city targets for terrorists.

(Journal entry Paula 12th September 2001)

Carol described herself as being "*in shock*" (Journal data Carol 11th September 2001) after seeing television coverage of the terrorist attacks. As well as being concerned for those involved, she also expressed anxiety about insulin supplies, and her inability to exert any control over the situation.

Should I get more insulin on my repeat prescription form in case there's a war and it can't be shipped/flown from Scandinavia? ... Feel so helpless. Want to do something to stop it, but can hardly move away from the TV.

(Journal entry Carol 11th September)

A few days later she again refers to the attacks and the impact upon her diabetes control:

Diabetes and diet totally up the spout ... keeping very busy to try to stop obsessing about the attacks.

(Journal entry Carol 14th September)

Her journal entries were supplemented by the inclusion of the picture below (Figure 6.2).

**FIGURE EXCLUDED
UNDER INSTRUCTION
FROM
AWARDING INSTITUTION**

Figure 6.2 *Newspaper cutting included in Carol's journal.*

The impact of wider events upon diabetes was an unexpected outcome of the study, and would not have been identified without the use of journals as a method of data collection.

This analysis has taken a view across the sample of the fifteen women who identified life events, and also discussed individual women's experience of these events in relation to living with diabetes. The majority of women described a single event, with Irene and Jane referring to a series of events and Tanya not identifying a time of crisis at the time of the interview. However, together with two other women, she identified global events in her journal, but unlike the other women did not relate them to her own diabetes, but to her philosophy of life.

Within the episodes identified by the women at interview, there was evidence of interruption to everyday life, lack of time to concentrate upon their diabetes, competing priorities and lack of opportunity to control the wider situation. Glycaemic imbalance was

a feature of many of the stories told, whether due to a physiological response to stress, or difficulties with self-management. If it was not possible to control the event, at times it was possible to control the diabetes in a way that was not necessarily optimal in biomedical terms, but that allowed the women to function in psychosocial terms.

The following section is concerned with the subtheme *health related episodes* consisting of the clustered themes of *psychological and emotional outcomes of living with diabetes*, *physical episodes that indirectly related to diabetes* and *diabetes-related physical episodes*. These were episodes directly experienced by the women themselves.

6.2 Health related episodes

This section is concerned with the exploration of physical or psychological health related episodes and outcomes described by the women and that have been co-constructed. All the women (with the exception of Tanya) were able to identify such episodes in relation to living with diabetes. Six of these accounts were obtained in response to the question asked in the context of general stress, and were identified as the most stressful events in their lives since their diabetes was treated with insulin. Claire and Janice both described hypoglycaemic episodes. Four women (Joy, Pam, Angela and Lynn) referred to medical events that were not specifically diabetes related.

A summary of these accounts is shown in Table 6.2. It can be seen from the table that the women’s experiences have been divided into reported episodes which were physical in nature and psychological/emotional outcomes of living with diabetes. The physical episodes may not have directly related to diabetes, but they either impacted upon, or were impacted upon by, diabetes.

Table 6.2 Physical or psychological/emotional outcomes of living with diabetes

Name	Physical Factors	Psychological/emotional factors
Carol	Pregnancy; hypoglycaemia; hyperglycaemia	Anger at being told what to do by other people; weight gain; feeling helpless; depression; anxiety
Lesley	Nothing identified	Weight gain
Josie	Nothing identified	Dislike of dependence upon insulin to live; weight gain; depression
Lois	Infection, cold sores	Nothing identified
Gina	Hysterectomy; Emergency hospital admission with diabetic coma	Nothing identified
Joy	Stroke; tracheostomy	Upset when told she was overweight by health care professional
Pam	Breast cancer	Fear of complications
Carla	Attending clinic	Fear of hypoglycaemia; weight gain
Angela	Joint replacement	Depression; anxiety
Lynn	Trapezectomy; Hypoglycaemia; Needles; Effects of tablet therapy	Binge eating; being overweight; depression
Irene	Maintaining glucose balance; dental problems	Worry about hypoglycaemia and complications; needing lavatory if hyperglycaemic away from home;
Jane	Eating regime; Pregnancy;	Worry about hypoglycaemia; depression; anxiety; attempted suicide; awareness of diabetes increased by blood testing
Tanya	Nothing identified	Nothing identified

Claire	Severe hypoglycaemic attack when driving, leading to unconsciousness	Loss of belief in previous good health; loss of self esteem; loss of freedom; fear of complications; "neverendingness" of diabetes
Judith	Nothing identified	Fear of complications and managing diabetes when unwell
Paula	Injections and blood testing	Fear of complications ; weight gain; depression
Joanne	Pregnancy; Coping on a daily basis	Consideration of suicide if complications develop; annoyance when everything attributed to diabetes
Joan	Complications of diabetes; pregnancy	Depression
Janice	Hypoglycaemia	Depression; overdose of insulin; weight gain
Marge	Pregnancy	Worry about complications
Carmen	Injections and blood tests	Nothing identified
Mandy	Pregnancy; illness	Fear of hypoglycaemia and complications; weight gain; depression; anxiety
Annette	Hypoglycaemia; pregnancy	Concern about responsibility of diabetes and its impact upon relationships; guilt regarding death of daughter; anxiety

6.2.1 Psychological/emotional outcomes of living with diabetes

All the women interviewed identified psychological and emotional outcomes of living with diabetes, with the exception of Tanya, Lois, Gina and Carmen. Four categories of psychological and emotional outcomes were co- constructed by the women interviewed

and are listed below and illustrated in Table 6.2. The numbers in brackets refer to the number of women identifying the particular outcome:

- Concern about weight gain (9)
- Negative responses to diabetes (10)
- Worry about hyperglycaemia – intercurrent illness and long term complications (7)
- Fear of hypoglycaemia (4).

a) ***Concern about weight gain*** Nine women expressed concern about weight gain in relation to their diabetes. Although weight gain clearly has an impact upon the physical aspects of diabetes, it is also known to have psychological and emotional outcomes in terms of self image and self esteem. At its most extreme it is linked to eating disorders, which are more common in women with diabetes as discussed in Section 2.1.3. Only one woman (Lynn) spoke about her weight gain in these terms. Managing her diabetes was complicated by the fact that she also suffered from psoriasis and arthritis, which in turn limited her mobility. She was aware that her diabetes was affected by her weight and acknowledged this, and her responsibility with regard to it:

I think it helps to have a binge now and again if you're not fat, and I'm fat, a bit overweight no, I'm fat and that's it, but I do admit, if I've had something I admit it.

(Interview data Lynn 1715–1718)

Although she was aware that her weight had a detrimental impact upon her diabetes control, and that if someone commented on her weight, that would upset her more than anything else, she appeared to almost challenge health care professionals with regard to her food intake and weight. She described an incident where she walked into the diabetes unit eating a chocolate bar and was called a '*naughty girl*' (Interview data Lynn 424) by

the diabetes specialist nurse, although she took this to be a sign of a good relationship between them. She also referred to the formation of a club – '*the sod it club*' (Interview data Lynn 1080) members of which were herself and her friend, who ate cakes together. This suggests a resistance to being regulated by health care professionals. She acknowledged that she sometimes skipped meals in order to lose weight, although she was aware that the potential outcome would adversely affect her diabetes. In the past she had been a yo-yo dieter, had her teeth wired when she reported that she had lost 10 stone, and used laxatives to control her weight. She reported that she felt her weight gain was partly attributable to her diabetes and her mother and father insisting that she ate every two hours, to avoid hypoglycaemia, and was at odds with her controlling her weight, and she had developed strategies to counter this.

I suppose I get quite depressed at times over it. I get depressed over the thought that you're supposed to eat regular, and you're trying to lose weight and you don't want to eat regular. It's like a conflict of interest.

Julie How do you resolve that conflict?

Lynn I don't.

Julie So what do you do?

Lynn Either don't eat anything and pass out, or eat something and take a laxative or two.

(Interview data Lynn 960–976)

Although Lynn was the only woman to refer to behaviour indicative of eating disorders, other women referred to ways of controlling their weight in relation to their diabetes. Janice reduced her carbohydrate intake as did Mandy, (and also her insulin), but had two hypoglycaemic attacks. Paula described trying to control her weight as '*a struggle with insulin*' (Interview data Paula 605), as insulin can cause weight gain, and she needed to increase her dose to regulate her blood glucose levels.

Lynn had referred to her sensitive feelings if people commented upon her weight, and this was shared by Joy and Pam. Pam was also grateful that health care professionals had not commented upon her weight, and Joy was very upset that a health care professional had called her fat. Although she acknowledged that she was overweight, she responded to the comment by describing not just the medical but the wider context of her life, and her reasons for wanting to control her weight and therefore her diabetes:

And I said, you know, to this Dr, ' you don't know me, you don't know my lifestyle, you don't know what I eat. It's all very well you saying that I'm fat and I'm overweight. I know what I eat', and that's why I feel that I'm in control, because if I want to be out of control with my diabetes, I can eat sweets and cakes and chocolates if I want to, or lots of pastry, because that's what I like, pastry, lots of things that I'm not allowed to eat, a lot of, but I don't want to have any complications and I don't want to miss seeing my grandchildren grow up. I want to be there beside them, watching them and seeing them do well.

(Interview data Joy 346–357)

Joy had joined a slimming club, as had Carla, and Carol was following a very low calorie liquid diet at the time of the interview. Lesley was deciding which diet plan to follow as she described herself as being very conscious of her weight.

In contrast, Pam saw poor control of diabetes as having a positive effect upon her weight. She was visually the most overweight woman of those interviewed. She saw her weight as the thing that had impacted the most upon her diabetes. She was aware that having persistent high blood glucose levels meant that she would lose weight, and was prepared to tolerate the symptoms of excessive thirst and passing urine to achieve this, although she was concerned about the development of long term complications, indicating conflict between the potential positive short term gain and long term negative health outcomes. Diabetes was not her major health problem, as she had had surgery for breast cancer.

- b) ***Negative responses to diabetes*** Ten women referred to major negative emotional and psychological responses to living with diabetes. These were:
- Depression and anxiety (10)
 - Anger and annoyance (2)
 - Concern about the responsibility of diabetes and guilt (1)
 - Dislike of dependence on insulin (1)
 - Loss (1).

All the women spontaneously referred to depression or anxiety. Six of these women had also referred to weight gain above. There is known to be a link between depression and diabetes (Section 2.2.3). Although Carol reported that she was taking antidepressant medication, she stated that she felt it was more to help her deal with stress, rather than because she had clinical depression. Josie had a very negative view of her diabetes so it is perhaps unsurprising that she reported such feelings. Joan referred to depression in the context of the development of the long term complications of diabetes, and Claire to her anxiety with regard to experiencing hypoglycaemia whilst driving and her lack of control in such situations:

It leaves a residue of anxiety in me that there are things happening that I can't do anything about and that is a bit scary really.

(Interview data Claire 718–720)

Jane stated that she felt that her depression was linked to her diabetes, her awareness of which was raised every time she tested her blood glucose levels. For that reason she did not test as often as she felt that she should. Paula stated that she believed that her depression stemmed from the fact that she had expected her diabetes to resolve following the birth of her second baby, as it had with the first. Both Angela and Lynn referred to being depressed, but as both suffered with the other long term condition of

rheumatoid arthritis and Lynn also with psoriasis, they found it difficult to pinpoint it to their diabetes, although Angela stated in her journal that she *'could do without diabetes'* (Interview data Angela 2854). Both did however state that feeling depressed had a negative impact upon their glycaemic control. Lynn's journal entry illustrates the cyclical nature of the link between diabetes and her other long term conditions (Figure 6.3), in terms of physical and psychological outcomes.

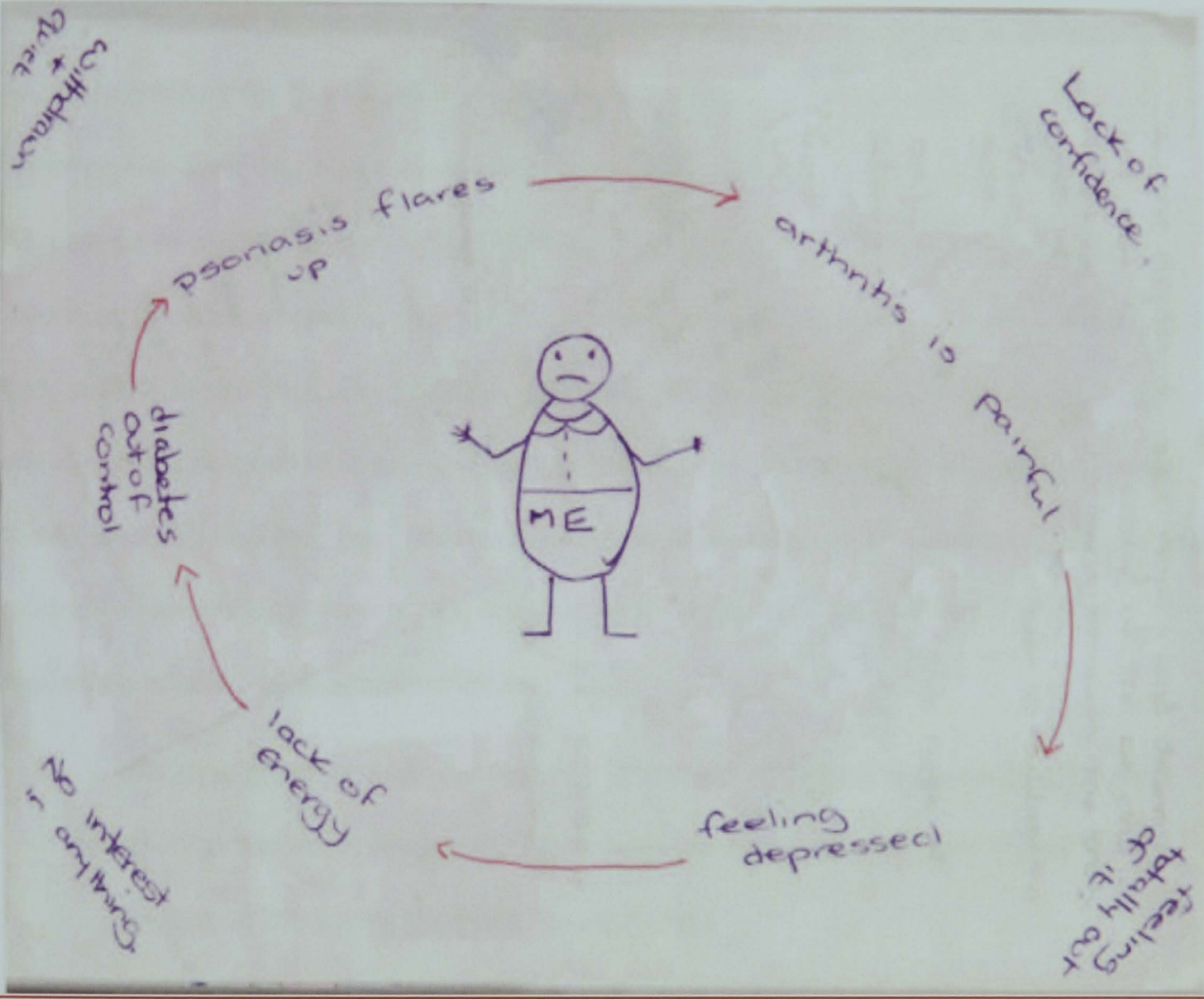


Figure 6.3 Lynn's depiction of the cyclical nature of the link between diabetes and her other long term conditions.

Both Annette and Mandy referred to being anxious, tense and fraught. Annette attributed this to finding everything about living with diabetes stressful, and for Mandy the psychological and physical³ symptoms were so severe that she gave up her professional

³ The fight or flight' hormones epinephrine and norepinephrine (previously known as adrenaline and noradrenaline) are produced in both anxiety and hypoglycaemic responses.

life. She also described diabetes as '*the most stressful thing in my life*'. She suffered severe panic attacks which lasted for two years, and reported that high blood sugars resulted in her feeling tearful and depressed, and that at times it was difficult to differentiate between hypoglycaemia and anxiety.

Three women referred to suicide in relation to diabetes, Joanne in relation to dealing with adverse events in the future which she feared she would be unable to deal with, and Jane and Janice as a strategy for dealing with current difficult situations. Joanne had considered it for the future if she developed long term complications of diabetes affecting the eyes, but had subsequently decided against it. She did not refer to depression or anxiety in any current context. Jane and Janice also referred to using insulin as a means of ending their lives in a more immediate context and both stated that they suffered from clinical depression. Jane referred to using insulin in this context when she described a series of events happening '*all at once*' (Interview data Jane 1004), and Janice also referred to using insulin when feeling depressed, which she described as being related to low blood glucose levels, suggesting a cyclical process between feeling depressed and low blood glucose levels.

I am slightly depressed now actually. It started on Saturday morning, and when was it? When was I feeling ill? I felt really low and I actually gave myself an overdose in the evening before I went to bed.

Julie Deliberate?

Janice Deliberate, yes. I haven't told anybody here at all, so that's a secret, yeah. I gave myself 30 Actrapid. Of course, I woke up in the night with an enormous hypo with (husband) giving me sweets and things. That's the first time that I've ever done that, mind you, and I was very glad that it didn't work in the morning of course. But that is just..., I was feeling really low for some reason, I don't know, just really fed up, so

*that's the only time that I've done that, let's hope it's the last time, yeah,
God, I don't want to do that, no.*

(Interview data Janice 543–562)

Anger and annoyance were expressed by both Carol and Joanne. Carol described the most stressful thing in her life relating to her diabetes as being when other people told her what to do in relation to her diabetes, whether it was a health care professional or someone well meaning. She described herself as being *'jealous of my rights to decide for myself what my life is going to do'* (Interview data Carol 2434–2435), and saw any impingement upon this as an infringement of her rights. Joanne described feeling intense annoyance when other people attributed things that could not be explained in any other way to her diabetes and the uncertainty and distrust this engendered in relation to health care professionals. She refers to this in her journal:

On my last visit to the opticians she could not prescribe 100% correction. My blood sugar was in the normal range so she said 'I can't get it any better. Let's just say it's because you're a diabetic and leave it at that'. Did she know something she didn't want to disclose or did she really not know? Least ways it is an explanation I find hard to tolerate.

(Journal entry Joanne 5th August)

Concern about the responsibility of diabetes and the resulting impact upon relationships was expressed by Annette together with feelings of guilt she experienced following the death of her daughter (Section 6.1.3). She also described herself as feeling *'riddled with guilt'* (Interview data Annette 1421) about the effect that diabetes had upon her close relationships, particularly her husband. She stated that she felt that control of her diabetes was her responsibility, and that if she became hypoglycaemic, the responsibility lay with her. She described a situation where she spat glucose solution at her husband during the night, and how this had necessitated a complete change of bedclothes. She

was able to stay at home and recover the next day, whilst he had to go to work, when he also suffered from health problems necessitating self-management. She experienced extreme guilt after the event, which set up a vicious cycle of physiological and emotional reaction, as stress had the effect of inducing hypoglycaemia.

Dislike of dependence upon insulin was voiced by Josie. For her the most stressful thing about living with diabetes was:

Knowing that if I don't take my insulin I'm going to die. If I don't look after myself things will start dropping off, you know. That sort of thing. I'm not.., it's only going to get worse, so I need to look after myself now really, for when I get older, but also will I get old?

(Interview data Josie 688–692)

This also echoed feelings of responsibility and fear of complications and death as expressed by other women.

Loss was a major issue for Claire. It was a recurring theme throughout her interview. She referred to loss of control in the work situation, loss of spontaneity, loss of freedom, loss of belief in good health affecting her self concept and self esteem. She described herself as going through a grieving process where she felt angry and upset. Her journal (which she wrote in the form of letters to me) continued to reflect this sense of loss:

Another resonant theme from yesterday is that of 'loss'. After the initial diagnosis sinks in there is the pain of accepting the loss of your good health. Alongside this is the 'neverendingness' of it – that's when I think you need some emotional support.

(Journal entry Claire 1st August)

- c) **Worry about hyperglycaemia** Seven women referred to worry about hyperglycaemia, which was divided into the short term effects when other illness such as infection was present, and the development of long term complications.

Irene and Judith reported their discomfort regarding the short term effects of hyperglycaemia. Irene enjoyed travelling long distances, and found it extremely stressful if her blood glucose levels were high if she was travelling with other people, and she needed to pass urine very frequently. She described feeling embarrassed at being the unwanted centre of attention and disrupting the journey for everyone else. Judith described when she was unwell, perhaps with a viral infection, as a time when '*I really cannot ignore it and I take it a lot more seriously*' (Interview data Judith 84). She tested her blood more frequently and she described the fear that she felt when she was unwell and had been admitted to hospital on several occasions.

And it's frightening when it's out of control big time because there's nothing you can do about it. I've laid down here on that settee thinking that I was going to die, and when you're on your own, it's hard, you know. If (daughter) gone to college and you know your sugar levels are right up, and you've got to get them down, and you're maybe sick with diarrhoea, and some tummy bug or something, it is frightening, it is really frightening. I mean, before I had it I never got as frightened as that, it was always just a tummy bug and it'll go within a couple of days, but you are absolutely pummelling ice water down you, and bringing it up because you're feeling sick, and you don't what to do. You do not know what to do, it's horrible. You're sweating, you're very tired, you're frightened to go to sleep because you might go into a coma, even though you won't because your levels are up there, you still feel that you ought to drink, and the only way they really sort that out is by taking me in and putting me on a drip. I know I sort of know that that will eventually happen, but you're trying to put it off.

(Interview data Judith 1560–1579)

As well as being concerned about the short term complications, both Irene and Judith referred to the fear of developing long term complications as being a worry, as did Pam, Claire, Judith, Paula, Marge and Joanne. All the women demonstrated a clear understanding of the potential impact of diabetes in the long term, and some had already begun to experience the effects of prolonged raised blood glucose levels which can affect the major organs of the body including the heart and circulatory system, eyes, the nervous system and kidneys. Pam and Marge both referred to their failing eyesight, with Pam being aware of the need for regular screening, due to lack of symptoms in the early stages. The impact of this for her was that she was no longer able to drive, which affected her lifestyle greatly. She referred to the fear of developing the complications as always '*being at the back of my mind*' (Interview data Pam 1499). This sentiment was echoed by Paula when she stated:

I was worried about retinopathy because I thought that probably was the worst thing I could think of that could happen. As time goes on, it's amazing, you do bump into people that are diabetic as well and you find a lot of them have got complications already, so I think that's always in the back of my mind.

(Interview data Paula 66–71)

She returns to this theme of always being on alert later in the interview when talking about stress in relation to her diabetes:

It's just the worry that you can't go on too long before it's going to catch up on you. I'm always thinking, 'is my toe going numb? Am I seeing OK or is it just perhaps that something's deteriorating slowly I'm not noticing it?' which is why I rely on having everything checked every year because you tend to rely on the Drs being more aware than you are of things that are going wrong. I do, I'm constantly waiting for some sort of complication to appear, and I'm just praying it's not going to be my eyes really, I think that's the one I'd cope with worst really.

(Interview data Paula 634–643)

Judith referred to her initial feelings when diagnosed that diabetes was a '*death sentence*' (Interview data Judith 35), and her concern about who would look after her children, fears also experienced by Irene, who recalled her feelings when her children were young:

Oh my goodness, what have I done? I've had these 2 children and I'm not going to live to bring them up.

(Interview data Irene 177–179)

These fears prompted her to take proactive measures to avoid the development of complications, including exercise and taking supplements. She felt so strongly about it that she developed an information sheet to give to other people with diabetes (see Figure 6.4).

Claire described her fears in relation to the future, and her views as to where responsibility lay, when she referred to diabetes as being:

Another thing to put into an already hectic life with enough choices, then to throw this one in, because the weight of this one is not only for now, what it does to me now, it's the effect of what's it going to do when I'm 60, 70, 80? Is it going to be my eyes that go, is it going to be my feet, is it ...? You know I've just met a colleague of my husband's who's just had his leg off through diabetes. When you hear things like that you feel 'God I'm totally responsible for the next 20 years of my own health'.

(Interview data Claire 902–911)

- d) ***Fear of hypoglycaemia*** Four women referred to fear of hypoglycaemia as a major psychological/emotional outcome of living with diabetes, in the past, during the present and potentially in the future. For those women who had had diabetes for many years, their experiences of managing hypoglycaemia had developed over time. Mandy described it as the most stressful thing about living with diabetes, in

TIPS ON LIVING WITH DIABETES

- Eat little and often - this means blood sugar keeps on a more even keel.
- Nearly all the side effects of diabetes are caused by poor or defective circulation, therefore anything which improves circulation must be beneficial. Also, it is advisable to keep the immune system boosted as much as possible as frequent infections affect diabetic control adversely. I have tried all the strategies listed below and would certainly try others if I felt that I needed more help. e.g. acupuncture, massage, more exercise. The main thing is to keep as healthy as you possibly can. Don't smoke and try not to drink too much. It's particularly hard when you're young and a student but, provided you don't go too drastically off the rails, you can catch up in later life!
- Exercise a lot, particularly when high blood sugar. e.g. go for a walk/jog/play football after a big meal even if you feel like lead.
- Yoga is good for keeping internal organs in shape as well as exercising limbs. It can bring blood sugar down as some postures work specifically on pancreas and liver. Some exercises are very good for feet and toes and circulation generally. (I've been attending yoga classes consistently for 26 years).
- Supplements, i.e. vitamin pills, etc. I have taken garlic tablets for 26 years. Garlic is reputed to be particularly good for heart and circulatory problems as well as boosting the immune system generally. I also take a daily tablet containing antioxidants, i.e. vitamins and minerals, particularly vitamins A and C and chromium, magnesium and zinc, all of which are good for diabetes. There has been some study in Glasgow which showed that Evening Primrose Oil is beneficial to diabetics but I haven't taken it much to date. I now take something called Co-enzyme Q10 which helps the body to convert nutrients into energy. I started taking it because my teeth and gums were in an awful state. After years of diabetes, niggling things start to happen like abscesses on teeth and minor wounds not healing and the Q10 does seem to help.
- If you feel awful and don't know why, it may be that you have an infection or something which is making your blood sugar swing rapidly. If you test it, it may not look too bad as a one off test but, if you keep testing, you may see that it is actually going up or down too quickly and then you can take some corrective action. (If you do nothing, the feeling will probably pass anyway!)
- Always test if you feel bad even if you think you know why. When I was in my twenties, I ate a mars bar because I felt dreadful and I'd had nothing to eat so I assumed I was low blood sugar. I actually had glandular fever, my blood sugar was already sky high (before the mars bar) and I ended up in hospital!

NB Medical opinion about best practice for diabetic control has fluctuated **wildly** in the 47 years that I've had it and the best thing is to take all the advice you're given with a pinch of salt and use your own common sense and experience whenever possible!

Figure 6.4 Irene's tip sheet on living with diabetes.

that it affected the quality of her life. Hypos were reported as being a terrifying experience for her, which affected her emotionally afterwards. She felt unable to accept invitations to social events, as she found hypoglycaemia embarrassing in public places. As well as avoiding social situations, she also avoided meetings in the work situation, and the anxiety associated with this led to her resigning from professional life. The issues of risk and responsibility affected the type of work which Jane and Irene undertook. Jane had no memory of caring for a young child in her care following being hypoglycaemic, and was so afraid of it happening again, that she changed her work life completely. She was also concerned about future attacks, as she had experienced two bouts of unconsciousness whilst pregnant, which had resulted in memory loss. Irene also described how she was concerned about becoming hypoglycaemic in the work situation, as her work involved communicating with other people. She reported catastrophising the potential outcome, by becoming claustrophobic and experiencing a panic attack.

Carla vocalised that she saw every hypo as a failure of her taking responsibility for her diabetes. Her main fear was dying during a hypoglycaemic attack, when she was not ready for this.

I'm so damned scared of hypos and I'm certainly scared not to wake up one nice day and I don't think that would be very amusing, it would be very messy. Just look at my study, my desk at the moment.

(Interview data Carla 559–562)

Five other women referred to their experience of hypoglycaemia as a physical event, and these accounts will be examined in the following section relating to those physical episodes directly related to diabetes.

6.2.2 Physical episodes indirectly related to diabetes

Within this clustered theme relating to *health related episodes*, four women identified physical episodes which were not specifically related to their diabetes as being the most stressful events in their lives since their diabetes was treated with insulin. Joy, Pam, Lynn and Angela all referred to other health problems which had necessitated surgery and hospital admission, and there were common themes to their experiences in relation to their diabetes. All four required surgery – Joy an emergency tracheostomy for throat cancer; Pam surgery for breast cancer; Angela a joint replacement for rheumatoid arthritis and Lynn a trapezectomy, also for arthritis, and all reported an impact upon their diabetes.

All four women were starved the morning of the operation and an intravenous infusion was commenced, and they all reported a change to their normal routine, in terms of insulin administration, reduced activity and change in diet. Both Pam and Lynn reported episodes of hypoglycaemia during their hospital stay. Pam described combined care from a diabetologist and anaesthetist, and Angela described being given additional care by nursing staff to avoid diabetes related complications.

Both Angela and Pam stayed in hospital longer than expected – Pam because of a wound infection, and Angela due to complications during surgery. Pam's expected stay was three days, and this was extended to nine, and Angela was hospitalised for three months. Lynn's operation would normally be carried out as a day case, but she stayed overnight as she had diabetes.

Joy described the worry on her husband's face as a source of stress, which adversely affected her blood glucose levels and she became hyperglycaemic. Her account suggested a degree of conflict with health care professionals. As she was unable to speak she communicated in writing that she needed to be in control of her own diabetes, particularly in relation to blood glucose testing. However, she needed to be assertive in order to be in control.

I said to her (Nurse), 'if you take this drip out, take this sugar away from me, then I'll know what I'm doing.' 'Oh I'll have to see sister'. I said 'if you don't take it out then I'm taking it out because you're giving me all this sugar and then you're insisting that I'm eating, pumping it up, you're not taking into consideration that I've had this operation, which is stress to my body, and is making my sugar go high. There's also this high quantity of sugar going in on the drip, then you're insisting that I'm eating, and you're not compensating it by giving me any extra insulin.' They'd also put me on an injection for, can't remember what it was called, 'cos I'd actually got a throat infection as well. Steroids. And it was the steroids that were pumping the sugar high, we didn't know at the time, and because my hand had all bruised, he read my notes and went and got the sister, and she 'oh no my love, we can't take it away', and I said 'either you take it away, or I don't eat, or you know, something drastic's going to happen here.

(Interview data Joy128–1306)

She was proved to be right, as when the intravenous infusion and the steroids were discontinued, her blood glucose levels decreased. Her diabetes also impacted upon the situation, as the result of the hyperglycaemia was an increased need to pass urine. Joy found using the bedpan very uncomfortable, but managed to negotiate the use of a commode. Her account reflects her having to fight the system and the hierarchy, as well as recover from major emergency surgery.

Angela's story had a similar tone. As well as dealing with complications and a prolonged hospital stay, she was also at times at odds with the hospital system. She was unable to obtain the appropriate lancets for her own blood glucose meter, and was therefore forced to queue for the use of the one belonging to the ward, which frequently went missing, at a time when she was receiving insulin via a pump requiring additional blood glucose testing. She had to provide her own snacks to ensure an adequate carbohydrate intake. She described diabetes as '*an extra dimension, an extra complication*

to things' (Interview data Angela 348–349). Lynn also described additional difficulties as a result of having diabetes, such as her husband giving her insulin, and her blood glucose levels rising as a result of arguments with her husband about him undertaking aspects of her physical care. She also reported delayed wound healing following surgery.

Angela recalled that her insulin was given at the wrong times, and she had difficulty in negotiating the correct insulin dosage to control her blood glucose levels. She described a lack of flexibility and understanding, and took matters into her own hands by telephoning the diabetes specialist nurse directly to work with the ward staff, which resulted in some friction. However, she explained that she felt justified in doing so and indicated ownership and responsibility for her own diabetes.

Perhaps I shouldn't have phoned them up in the first place, but I wanted, it's my diabetes, my body, I wanted to know that the right thing was being done, what I thought, well I know what is right for me.

(Interview data Angela 394–397)

Pam reported that her wound took eight weeks to heal, and this was attributed to delayed healing due to diabetes. Once home, radiation burns which occurred as a result of radiotherapy also took a prolonged period of time to heal. However the major impact for Pam upon her diabetes was a positive one, in that her blood glucose control had been much better controlled since the surgery and she tentatively attributed to the drug therapy she was also receiving.

This section has demonstrated the complexity of being a person living with diabetes within a psychosocial context, and highlights the importance of the consideration of personal experience within health care consultations. The women's experiences of hospitalization demonstrate how the system failed to address them as individuals with multiple roles with a life outside the hospital. The experiences were in general disempowering, with the women reporting a lack of control and ownership of their

diabetes and feeling trapped within the situation. This has important implications for the delivery of diabetes care and will be further discussed within Chapter 9.

The following section is concerned with the clustered theme of *physical episodes which are directly related to diabetes*.

6.2.3 Physical episodes directly related to diabetes

The previous section has examined physical episodes which were indirectly related to diabetes. This section will discuss the clustered theme of *physical episodes directly related to diabetes* and focuses on the embodied experience of diabetes. The episodes were broadly divided into two categories:

- Pregnancy
- Impaired blood glucose control.

Pregnancy

Seven women (of the twenty one who had been pregnant) described pregnancy as a major event in their lives with diabetes. Their accounts suggested that pregnancy was a time of crisis for them, as they had all experienced difficulties during this time. Jane developed diabetes shortly after her marriage and both she and her husband were upset to be told by a health care professional that they would be unable to have children. However, they went on to have three. Jane was hospitalised for two months with her first baby due to raised blood pressure and for monitoring as home blood glucose monitoring was not the norm at that time. She was induced for all three deliveries, and all babies went to the Special Care Baby Unit for monitoring – all of which she felt was worrying and unnecessary. Joan was also diagnosed with diabetes shortly before becoming pregnant with her only child, who was born by Caesarean section, as was the norm at that time. She was severely hypoglycaemic the day following the birth and progressed into a coma. The outcome was that she was afraid of being alone for many years afterwards. Joanne

also recounted how she spent her '*difficult pregnancy existing in a hypo*' (Interview data Joanne 115) as she was worried about high blood sugars for the baby's sake. She was aware of the dangers of delivering a large baby and the potential for the development of congenital malformations. Annette also recounted that she spent a lot of time with low blood glucose levels, however there were also periods of time when they were high, which she felt were difficult for her husband to cope with. Although she reported that she did not find her pregnancies enjoyable, she always followed the advice she was given by health care professionals. She delivered three children, one of whom later died as a result of a congenital heart defect, and she continued to question whether this was due to diabetes, and experienced guilt as a result, as she could never have a definitive answer.

Marge, Mandy and Carol all described distressing situations which occurred in hospital during pregnancy, and which were connected to their perceived lack of control of the situation. Marge had not carried a baby to term, and was in hospital following a miscarriage, of which she had had several. She needed dilatation and curettage following the miscarriage, to prevent complications, and was upset to be in a maternity ward, with mothers and babies. She had become temporarily paralysed following anaesthetic, and was told that stress was not related to a high blood glucose level. She found the attitude of the staff insensitive, and discharged herself:

I actually signed myself out the next morning. I didn't even wait for the paediatric people to come round. Because they'd already said to me 'oh we're fascinated by all your miscarriages. Next time you're pregnant let us know and we'll have you in and monitor it going wrong'. I decided 'I've been headhunted, I've got a good job, and I'm not going through this again'.

(Interview data Marge 1535–1541)

Mandy had one child who was delivered by Caesarean section. She reported having little faith in the ward staff and secretly checked her own blood glucose hourly without their knowledge. Her insulin requirements had risen from 12 units a day at the beginning to 90

units by the end of pregnancy. Insulin dosage following delivery normally reduces, and eventually reverts to the pre pregnancy dosage over varying periods of time, so she was understandably alarmed when a midwife insisted that she receive the increased dose via her intravenous pump. To avoid this she removed the IV needle herself, so that the dose could not be given. In spite of a diabetologist visiting her and agreeing that she was correct, she did not receive an apology, and reported that she felt like a '*naughty child*' and a '*bad girl*'. Although she had felt infantilized by the health care staff, she felt enabled to take control back over her body, albeit subversively.

Carol spent a considerable period of time in hospital during pregnancy. She had suffered a number of miscarriages, and was hospitalised from twelve weeks of pregnancy until following delivery of her only child. She had a sense that the miscarriages were as a result of her previous management of her diabetes, and that she was being tested:

I don't believe in God, but it was as though there was a big sign up there saying 'God's going to pay you back' you know. Having lost a huge number of (SIGHS) I really felt that this was, once I'd got over 14 weeks that this was the test and I would either pass it or fail it, which is a very distressful situation to put yourself. Nobody else said that to me, I just ..., that's the way I felt.

(Interview data Carol 2072–2079)

Like Mandy she insisted on giving her own insulin as the ward staff had tried to give her twice her normal dose, and she also felt labelled as a '*bad patient*' (Interview data Carol 74), even though a doctor proved her correct. She described that she had '*won a few concessions*' (Interview data Carol 70) by giving her own insulin, although she had described diabetes as a '*no win situation*' (Interview data Carol 480) and '*a game you couldn't win*' (Interview data Carol 26). She wanted to learn as much as possible about diabetes and pregnancy and accessed medical articles which she was '*told off*' (Interview data Carol 210) for reading. She shared views voiced by Angela at the end of

Section 6.2.2 regarding ownership of her body. She described how she felt during the incident regarding insulin administration:

Made me pretty angry and pretty frightened, and I just happen to believe that my body is primarily my business, and I know it better than anybody else.

(Interview data Carol 82–85)

Feeling disempowered during her hospital stay led to an incident which Carol clearly found extremely distressing. She was suffering from a skin condition which she attributed to hormonal changes during pregnancy. One of the nurses, to whom she referred as a 'green dragon' (Interview data Carol 2196) commented on this, and called her a 'walking plague' (Interview data Carol 2217). Carol reports a spiralling of the situation as she became emotionally distressed, which led to an increase in her blood pressure. The ward staff wished to sedate her, which led to more emotional distress. The sedation was about to be given to her forcibly when her husband arrived who negotiated a review of the situation in thirty minutes. Her blood pressure decreased and the sedation was not administered. Carol found the situation distressing from a physical and emotional point of view, but also because her husband had been able to negotiate a compromise where she had been unable to do so, and had negotiated without recourse to her wishes. She describes the implication of the incident for her future relationships with health care professionals:

It was torture, it really was, and again that was a problem and has meant problems building any kind of trust that I might have had for the medical profession. I mean, how could they do that? Anyway, well they did it because they were looking only at my blood pressure and not me as a person.

(Interview data Carol 2259–2264)

Her problems did not end with the birth of her daughter who was incubated, which made breastfeeding difficult. Carol made the decision to run her blood glucose levels higher

following the birth as she did not wish to become hypoglycaemic whilst caring for her baby. However, she reported that health care professionals were unhappy with this and '*they won*' (Interview data Carol 2180). Although she would have liked another child, she made a decision to be sterilised, as she was specifically told that she could go blind if she became pregnant again, and felt that this would be unfair to her existing, and any future, children.

Impaired blood glucose control

This section is concerned with hypoglycaemia, short term hyperglycaemia in relation to illness, and long term hyperglycaemia leading to long term complications of diabetes, in relation to the category of impaired blood glucose control.

a) *Hypoglycaemia*

Fear and experience of hypoglycaemia were common to all the women interviewed. Two women, Claire and Janice, described hypoglycaemic attacks as the single most stressful event since they started taking insulin, both of which had occurred whilst driving.

Claire was alone, and had been to visit her mother, who was in long term care. She decided to carry on and do some shopping at the local supermarket on the way home. The last thing that she reported remembering was leaving the car park at 4.30, which was five minutes from her home. She remembered waking up at 6 o'clock, still in the car which she had parked near her home, and seeing her husband walking along the road looking for her. She did not remember having any warning symptoms. She was aware that she had a tendency to carry on with things and called herself '*Mrs Control*'. She did not recognise when she had done enough, which had not been a problem prior to being diagnosed with diabetes. She found the alternative of having to have a rigid timetable difficult to accept, as she wished to remain in control rather than the diabetes. However, she did not have sufficient physiological feedback to do so.

I wish there was just some little signal that, you know, my arm went green or something that says 'don't do it C, go and sit in the garden or have a cup of tea'. You see, I hadn't had a cup of tea, but I truly remember sitting in the car park at my mother's place actually asking myself 'how are you?' and I remember feeling so pleased that my mother wasn't weeping and wailing therefore 'oh great, I'll now go and do 65 things', but the alternative to me is 'do I have to have a rigid timetable that says "every day at 4 o'clock I have to be at home having a cup of tea and a rich tea biscuit?"' I just find that so frustrating and I suppose if I'd have had many more of these then I would change my behaviour, but that's the worse one I've ever had.

(Interview data Claire 657–669)

This lack of control regarding hypoglycaemia had implications for her career, as changes to the structure of the organisation in which she worked meant that she would potentially be driving long distances on a regular basis.

Janice had two daughters and her experience of hypoglycaemia had involved one of her teenage children. They had been out for the evening, and she described her daughter saying that she was driving erratically and dangerously. She had no memory of the situation and was reporting the experience as it had been told to her by her daughter, who described her as being very aggressive. She remembers stopping the car on the pavement, very close to a lamppost, and clearly found this distressing when she was talking to me. Someone stopped who had been driving behind her and took her and her daughter home. The long term outcome was that she now always tests her blood glucose level before driving, as she was aware of the potential danger of the situation and the distress caused to her daughter.

b) *Short term hyperglycaemia*

Four women referred to the outcome of severe short term hyperglycaemia (known as ketoacidosis) as a time of crisis. Carol described having diabetic ketoacidosis as a

teenager, both as a result of an infection and also due to her ignoring her diabetes.

Diabetic ketoacidosis is a potentially life threatening situation, and she described being in hospital and being unable to breathe, and feeling terrified. She describes herself as having the knowledge to prevent it but also denying it. Judith also described situations relating to short term hyperglycaemia, such as when she experienced diarrhoea and vomiting. These were⁴ times when she took her diabetes control seriously, and monitored and adjusted her insulin accordingly, as it was a frightening time. Mandy also described her management of diabetes during an illness as '*like climbing a mountain*', chasing to try and catch up and the frustration of feeling ill and having to monitor and give more insulin at the same time.

Infections were also of concern for Irene and Lois. Irene's dental problems of abscess and dental decay were attributed to a high level of glucose in her saliva, which affected her teeth adversely, and in turn the infection had the potential to affect the control of her diabetes. Lois developed severe cold sores when she contracted a cold. They had been so severe that she had been hospitalised with intravenous antibiotics, and they took more than a month to heal. She was so concerned about developing them after a cold that she took antiviral agents as a preventative measure.

c) ***Long term hyperglycaemia***

Although many women referred to fear of complications, only Joy and Joan described them as the most stressful thing in their lives since taking insulin. Joy had suffered a stroke, and was afraid of having a second one. Prior to the development of complications Joan had been a successful professional woman. She had developed complications affecting her gastrointestinal and renal system; eyes and cardiovascular system affecting

⁴ Diabetic ketoacidosis occurs when the body breaks down fat, instead of glucose to use as a fuel. This occurs when there is insufficient available insulin in Type 1 diabetes, often during times of illness and infection. Ketones are produced when fat is broken down, and the level builds up, resulting in increased acid levels in the body which can be life – threatening.

her blood pressure and breathing. She was worried about these progressing to gangrene or requiring heart bypass surgery.

Her journal entry below illustrates her feelings and experience of living with the complications of diabetes:

During the year it was suggested that I had an islet of Langerhans transplant. I was put forward but eventually rejected after being told I was top of the list.

Felt very depressed during the year. Problems seem to be getting worse. Have had test regarding atherosclerosis on legs.

Have had physio for shoulders and now seeing doctor regarding operation.

Still very breathless and hardly go out. Hardly drive car as days very short and don't drive in bright light or darkness.

Digestion is a real problem with gastroparesis and feel very uncomfortable.

Right eye often very bad. Can't have any more treatment.

Didn't feel I could go on holiday as short of breath.

(Journal entry Joan 2nd January)

The sense of sadness and despair was echoed in her interview, and she now seemed to be defined by her diabetes.

This section has been concerned with episodes and outcomes that have been defined as psychological/emotional and physical – the latter being directly or indirectly related to diabetes. These clustered themes relate to the subtheme of *health related episodes*, which is a constituent subtheme of the major theme of *diabetes at times of crisis*.

The following section is concerned with Gina who experienced a combination of events. Her story demonstrates different levels in the complexity of living with diabetes

when combinations of events occur simultaneously. Single case studies are increasingly being used in IPA analysis in terms of an idiographic presentation.

6.3 A complex situation

This section is concerned with the third subtheme of the major theme of *Diabetes at Times of Crisis*. It consists of the two clustered themes of life events and health related episodes, which are considered in an integrated way as this is how the episodes occurred. They were not discrete entities, but occurred concurrently within a short time span.

At the time of interview, Gina had been diagnosed with diabetes for forty one years, and the events described had taken place thirteen years previously in 1988. Gina's account has not been included in the previous section where concurrent events were explored (Section 6.1.6), as her experience relates to both life events and health related episodes. She was the only woman who reported a combination of both at the same point of time, although others may have experienced both at different times.

The bulk of the data used came from her response to the introductory question asking her to relate her experience of living with diabetes, and also to the question asking her about an event that she found particularly stressful since having diabetes, but has been supplemented by other data gathered throughout the interview.

Gina described several traumatic events that occurred in a six week period of time. They were (in chronological order):

- Sudden visit of her ex husband after nine years absence – life event
- Hysterectomy – health related
- Sudden death of mother – life event
- Separation from current boyfriend and loss of best friend- life event
- Emergency hospital admission with diabetic coma – health related.

Of all the events she described, the death of her mother had the most impact upon her life and her diabetes in a similar way to Mandy's experiencing the death of her father (Section 6.1.3). The distress she displayed during the interview was related to the loss of three close relationships, and also of diabetes control. In addition to loss, there was an overwhelming sense of the guilt which she reported feeling due to not being with her mother when she died, as also reported by Annette in relation to the loss of her daughter (Section 6.1.3). In common with other women referred to in previous sections, she described keeping things at the back of her mind (*'little box at the back'* Interview data Gina 1501), including diabetes. However, she was forced to give her diabetes immediate attention when her blood glucose levels rose quickly and drastically, and she was admitted to hospital, as was Judith (Section 6.2.1). Her view was that there was a two way relationship between diabetes and the events described; diabetes because she still had to adhere to diabetes routines and the events because her blood glucose levels became unstable.

You inject your insulin and you eat, and you eat so much and then you eat so much again and then you have another injection, and that really I suppose was the main focus of the diabetes to me up to then, it was as long as I ate the right food I was OK, and it wasn't until that happened that I suddenly thought 'hang on a minute', you know it's not just a physical thing here. Something mental's happened here that's affected it as well. I can't actually say I understand why, all I know is it did, you know, and I am 100% sure that it was the emotional thing rather than anything physical.

(Interview data Gina 1545–1555)

Gina viewed herself as being in charge of her diabetes, having been diagnosed for forty one years. Although she stated that she thought that she was maintaining an acceptable level of physical health, her reference to a diet of cereal and biscuits suggested that that

this was not necessarily the case. This could be interpreted as another case of '*purposeful blindness*' (Section 6.1.1).

She described a sequence of events that she perceived as being stressful and affected her diabetes, but there were also physical events which may also have affected her blood glucose levels such as poor diet and a hysterectomy.

Guilt was the main emotion to which she referred to in relation to her mother's death, and also because she entrusted her adolescent daughter to her mother's care, when she was aware of alcohol abuse. She was able to rationalise why she did not return to her mother's house following her hysterectomy, but this did not lessen the guilt. The roles that she described missing her mother undertaking bore a striking resemblance to the roles that she was now undertaking within her own life.

The culmination of this series of events which occurred within six weeks was her hospital admission with diabetes ketoacidosis. She perceived it as being due to a mixture of physical and emotional factors. Although this made sense in physiological terms in relation to blood glucose levels and stress, she had difficulty convincing health care professionals of this, with the exception of one female doctor. This parallels Joy's experience of trying to convince health care professionals during her hospital admission that she knew best about her diabetes (Section 6.2.2).

At the point of being hospitalised she had a choice – to become a passive victim to diabetes, or to continue to take an active role and move forward with her life. She reported taking the latter approach during her interview, and chose not to keep a journal as she reported that she did not perceive anything of relevance to report.

It's strange what you have to do when you have to. You haven't got much choice really you know. It's sort of 'oh I couldn't do that'. You would if you have to. But I suppose really it's never been a big deal, you know it's just how it is, and I've just got on with it really.

(Interview data Gina 203–208)

This section has considered the experience of one woman who reported the experience of a combination of events within a six week time period, and her perception of the interaction between stress and her diabetes, and has indicated where her experience overlaps with that of other women interviewed.

At the time of the interview the women perceived episodes and outcomes identified in this chapter as stressors at times of crisis in relation to living with diabetes. Their interpretation of events can only be subjective and variable between the women interviewed, with the short and long term effects of stress being discussed. A variety of views about their diabetes was expressed, ranging from it being an additional thing to consider, to it constituting the whole of a person. Their accounts have demonstrated that life with diabetes is complex and that settings and situations are interrelated.

The following final data chapter examines the overarching themes of experiencing stress and maintaining control, which are interlinked with the major themes, subthemes and clustered themes discussed in the first three data chapters.

CHAPTER 7

Experiencing stress and maintaining control

This last of four data chapters is concerned with the overarching and interlinked themes of *experiencing stress* and *maintaining control* in the context of living with diabetes.

These themes are considered in this final data chapter as they were constant threads throughout the three major themes of *diabetes as a nuisance*, *diabetes in daily life* and *diabetes at times of crisis*, which were considered in the preceding three chapters.

7.1 Experiencing stress

Women were asked about their experiences of stress specifically in relation to living with diabetes. Stress was self defined and was reported by the women as either being an event in itself or as a response to an event (Section 2.2), and was seen as being related to expectations in relation to both managing diabetes and other aspects of their lives, imposed either by the self and/or others. A degree of stress was viewed in a positive sense as being enabling and necessary, but conversely stress was also perceived as negative and inhibitory. A balance may be required to maintain the equilibrium between positive and negative aspects of stress, however the line between the two may be difficult to demarcate. Experiences of stress were described as having physical, emotional and behavioural outcomes, with interactions between these three categories. Claire described her experience as '*a vicious circle of intervention and weariness*', (Interview data Claire 592) a theme reinforced by Angela who also described her experience as '*a vicious circle*' (Journal data Angela). This introduces the concept of a dynamic process, seen in negative

terms, with regard to the physical effects of stress not having an end, but being part of a continuous circle unless it is broken by a change in events. If a change occurs in the experience of stress and diabetes, either by an increase or decrease in intensity or number of stressful events, the circular process has the potential to becoming a spiralling one, in either an upwards or a downwards direction, depending upon the nature of the change. Diabetes control may be affected in a positive or negative way depending upon the direction of change, and may itself be a factor that influences the development of the spiral. The experiences of the physical, emotional and behavioural responses to stress reported by the women in this study suggest that they are complex and interdependent processes which may be context specific.

In addition to being asked about their experiences of stress, the Living with Diabetes questionnaire (LWDQ) included asking women specific questions regarding stress in relation to their diabetes (Appendix 2). Table 7.1 illustrates the responses of the individual women to the questions asked. This survey data is supported by data from interviews (reported in the previous data chapters), where 70% (n=16) identified major physical events related to their diabetes as stressful and 91% (n=21) identified psychological and emotional outcomes of living with diabetes as stressful.

This table shows that slightly more than half of the women interviewed identified that they found living with diabetes stressful (n=13, 57%), the vast majority that stress affected their diabetes (n=21, 91%), and three quarters that stress affected the way that they managed their diabetes (n=17, 74%). This data was collected three to six months prior to being interviewed.

Table 7.1 Responses to survey questions relating to the experience of stress and diabetes.

	Do you find living with diabetes stressful?	Does stress affect your diabetes?	Does stress affect the way you manage your diabetes?	Duration of diabetes in years since diagnosis	Duration of insulin treatment in years
Josie	Yes	Yes	No	47	47
Mandy	Yes	Yes	Yes	20	20
Paula	Yes	Yes	No	20	20
Carla	Yes	Yes	Yes	14	14
Carol	Yes	Yes	Yes	41	41
Jane	Yes	Yes	Yes	20	5
Irene	No	Yes	Yes	10	3
Joan	Yes	Yes	Yes	11	7
Pam	Yes	No	No	9	6
Lynn	Yes	Yes	Yes	6	1
Claire	Yes	Yes	Yes	47	47
Carmen	No	Yes	Yes	26	26
Janice	Yes	Yes	Yes	3	3
Joanne	No	No	No	5	5
Angela	Yes	Yes	Yes	17	16
Annette	Yes	Yes	Yes	20	20
Judith	No	Yes	No	38	38
Lesley	No	Yes	Yes	39	39
Tanya	No	Yes	No	25	25
Joy	No	Yes	Yes	46	46
Marge	No	Yes	Yes	20	20
Gina	No	Yes	Yes	20	20
Lois	No	Yes	Yes	36	36
%age	57	91	74	N/A	N/A

In relation to the three questions asked and identified in Table 7.1, the combination of answers given are shown below and further demonstrate the range of both perceptions and experiences with regard to the relationship between stress and diabetes:

- Nearly half of the women (n=10) reported that they found living with diabetes stressful, and that stress affected their diabetes and the way that they managed their diabetes.
- One third (n=7) reported that they did not find living with diabetes stressful, but that stress affected their diabetes and the way that they managed their diabetes.
- Only two women reported that stress affected their diabetes, but they did not find living with diabetes stressful and that stress did not affect the way that they managed their diabetes. Tanya and Judith were the women concerned. Both had other priorities in their lives. Within the group of women interviewed Tanya was unusual in relation to running her own high profile business, and Judith also had a busy working life and issues with her relationship with her teenage daughter.
- Only two women, Josie and Paula, reported that they found living with diabetes stressful and that stress affected their diabetes, but that stress did not affect the way that they managed their diabetes. Josie was struggling to cope with unpleasant physical symptoms which she found difficulty attributing to diabetes or the menopause. Paula was struggling with managing the family's financial situation, and was finding difficulty balancing her own needs against the needs of her family.
- Only one woman (Pam) reported that she found living with diabetes stressful, but that stress did not affect her diabetes or the way that she managed her diabetes. Diabetes was not the major health issue in her life, as she also had breast cancer.
- One woman (Joanne) identified that she did not find living with diabetes stressful; stress did not affect her diabetes or the way that she managed her diabetes.

7.2 The relationship between stress and diabetes

Seventeen (17/23, 74%) women reported that they perceived there was an interaction between stress and diabetes. Five categories of response were given when the women were questioned about the effect of stress upon their diabetes. This stress was extrinsic to diabetes, but had the potential to impact upon it. These responses were that there was no effect, the effect was unknown, blood glucose levels were erratic, blood glucose levels fell or blood glucose levels rose. These categories can be seen in the context of either a one-way or two-way relationship between stress and diabetes. The following sections focus on these relationships.

7.2.1 One way relationship between stress and diabetes

Of the seventeen women, seven reported that they perceived there to be a one way relationship between stress and diabetes. Without exception, the one way relationship reported by the women related to a uni-directional association with stressful experiences having an impact on their diabetes, rather than vice versa. Most (14/23, 61 %) women reported a rise in their blood glucose levels, although Angela, Jane, Annette and Jackie reported a drop in blood glucose levels as a result of stress. Liz and Irene reported their blood glucose levels swinging erratically from high to low. Gina likened stress to excitement, as did Joanne, and gave an example of being discharged from hospital and blood glucose levels rising while she was waiting to go home. Jane expressed frustration that stress was not predictable, and could not be accounted for in advance in terms of diabetes management, and Paula expressed the same frustration that it could not be worked out mathematically. Although Marge recognised that there was a relationship between stress and diabetes, she stated that she felt that there needed to be further research in the area, and welcomed this study for that reason. Irene, having been diagnosed with diabetes for forty seven years, used the term '*internalised*' (Interview data Irene 889) to describe her personal experience of diabetes, meaning that it was part of

her *'whole persona'* (Interview data Irene 2562). Although she acknowledged that stress could affect diabetes, she did not see diabetes having an effect on stress. She qualified her previous answers relating to stress in terms of diabetes as a nuisance.

I have described it as stress, but it's nothing that I couldn't cope with and I would probably just say really that it's more of a nuisance than actual stress in inverted commas.

(Interview data Irene 2924–2937)

7.2.2 Two way relationship between diabetes and stress

Ten women perceived that the relationship between stress and diabetes was bi-directional, with four women describing the relationship as a cyclical one. Those women described a cyclical or spiralling relationship between diabetes and stress. Lois referred to *'balance and control'* (Interview data Lois 1261) when she suggested that in order for glycaemic and psychological control to be present, the elements of diabetes management needed to be in balance. Joanne viewed the presence of diabetes as a stress itself, which had the potential to affect blood glucose levels, as did Janice. The presence of diabetes was something extra to think about, which added to her stress levels and made her *'edgy'* (Interview data Janice 595), which affected her blood glucose levels. Carol referred to the social implications of diabetes as the situation where her blood glucose levels were low, and suggested that the embarrassment of having to eat in public affected her still further. Carla recognised a two way relationship, but not necessarily in a negative way as she believed that positive outcomes could result if appropriate action was taken. Joy also referred to the cyclical relationship between stress and diabetes in terms of blood glucose levels being affected and Lynn also used cyclical terminology (Figure 6.3).

If you're in a stressful mood, then it does affect your sugar and then if your sugar's high it's going to affect you. It's like a circle and it goes round, it's like a case of what goes round comes round, so one has got to affect the other and then the other goes back round.

(Interview data Lynn 1597–1601)

Annette related her experience of stress and diabetes to the relationship between herself and her husband. She described how stress affected her blood glucose level, which in turn affected the stress in her relationship with her husband. She likened the relationship between stress and diabetes to a marriage.

I do think one affects the other, yes and I think that relationship is quite a difficult one, rather like a bad marriage, but with counselling it can be helped.

(Interview data Annette 1513–1515)

7.3 Defining the nature of stress

When asked what the word stress meant to the women, they frequently referred to the causes and effects of stress, rather than to the nature of stress itself. Joy stated that she did not really know what stress was, although it had an unsettling effect upon her.

I don't really know what stress is. To me it's the rats - I get nasty and snarl.

Because I'm not on an even keel, that's what it is. I'm not on an even floor.

(Interview data Joy 1229–1231)

Although the women were not always able to define the nature of stress, all acknowledged its existence by attempting to describe it in terms of their personal experience of its causes and effects.

Some women attempted to describe the nature of stress itself. Paula referred to the lack of boundaries in relation to the nature of stress, saying that '*stress can be*

anything. She acknowledged the existence and inevitability of stress by describing it as being '*one of those things*'; Carol, reinforcing this concept, questioned whether her perception of stress was that of '*normal stress*'; suggesting that there was an accepted definition. In contrast to this she stated that stress was a varied concept, and there was more than one type of stress, thereby challenging the accepted definition.

Stress was not necessarily seen as a static concept, but as dynamic, in relation to the context within which it occurred. Judith referred to degrees of stress and stated that hers was '*not life or death situation stress*' (Interview data 2132). Pam, Lynn and Jane saw it as a product of a progressive or cumulative process, with a temporal aspect, something which had the potential to build up, to the point where there would be an unsatisfactory outcome in physical or emotional terms.

I think it's a group of things that seem to be getting you down, maybe in a day, maybe within a few days and they all get on top of you.

(Interview data Lynn 1199–1201)

Angela viewed stress as being self induced, resulting from not meeting one's own expectations of the self, whereas Claire saw it as being mainly related to other people's agendas being imposed. Trying to meet such expectations could result in a situation of pressure and tension. Stress may manifest as feeling like '*an over strung bow*' (Interview data Irene 2379) as described by Irene. This analogy suggested that there is the potential for the women to snap and become ineffective if too much tension resulted. Jane, Claire and Carla also referred to the pressurized nature of stress. Stress resulting from such pressures could have an inhibitory effect on functioning, with both Judith and Joan describing circular processes of non achievement resulting from this, particularly in relation to the work environment. Gina and Janice both also referred to not being able to get things done as a result.

Stress is I think when I can't do what I want to do for some reason. I can't get things done, yeah, if something stops me.

(Interview data Janice 216–218)

Stress was seen as a positive thing by some women. In Joan's view, positive stress was seen as enabling and necessary, even essential for life. Carmen saw it as having a function in building resistance to cope with life and Claire saw it as a challenge, suggesting a continuum of levels of intensity of stress.

Well I suppose there's good and bad stress isn't there? The positive one is this heightened awareness of opportunities or problems to be faced, issues, and at that level I would think I react very positively.

(Interview data Claire 527–531)

Conversely, stress could also be perceived as negative and inhibitory: Claire perceived it in both a negative and positive light.

At the other end of the continuum there's the stress that's the nagging, perennial wearing down emotionally. I mean the first one is cognitively challenging, and as long as there's some reward from it I think it's emotionally safe, whereas the other stress, as we've described about my mother, is the ongoing chipping away at your ability to change anything, but yet the total responsibility on your shoulders for maintaining, usually other people's agendas, and I think I find that very very wearing.

(Interview data Claire 531–540)

The line between positive and negative stress may be difficult to demarcate, and Marge suggested that there was a point when positive stress became negative stress. This demarcation is a subjective one, and depends upon the experience of diabetes and/or the events occurring within the social context at the time.

Tension. It can be positive or it can be a negative force. And I think I put it on there, I feel that a certain amount of stress is probably a good thing, because it saves everything flopping about. Too much of it of course is going to produce ... too much of a negative stress is going to create other problems.

(Interview data Marge 2823–2829)

This might suggest that a balance is required to maintain equilibrium between positive and negative aspects of stress, and to prevent inhibition of function developing. This is linked to the concept of the spiral, where an event can influence the upward or downward direction of the spiral. A positive event during a difficult period, such as finding a job following a period of redundancy as in the case of Lois' husband, can facilitate the change from a downward to an upward direction. Conversely, experiencing the loss of a close relative as in the case of the death of Annette' daughter, resulted in a change from a manageable level of stress to an unmanageable one and to a downward spiral.

The definition of stress as an abstract concept was not straightforward for this group of women. Stress was seen as having an existence but not being a tangible concept, in effect being invisible. The development of stress was seen as a dynamic process, relating to context. Both positive and negative aspects were identified, with enabling and inhibitory outcomes respectively. Attempting to fulfil expectations, imposed by both the self and/or others was seen as contributory factors to the development of stress.

7.4 Diabetes-related stress

During the interview the women were asked about sources of stress in relation to their diabetes. Some women who had been unable to identify sources of stress in the LWDQ did so when interviewed, in spite of having reported one thing in the survey; they said something different in the interview. Marge and Joy referred to previous diabetes-related stress which had now resolved. Although Lesley identified diabetes-related stress, she

qualified this by saying that she was not overly stressed by her diabetes. Lois described it as an inconvenience rather than stress, Joanne stated that she had accepted her diabetes, and Tanya was not able to identify specific diabetes related stressors in her life in either the survey or the interview.

Those women who did refer to diabetes-related stress in their interview identified three sources of stress. These were: a) other people, b) short and long term complications and c) self management issues.

Stressors

7.4.1 Other people as a source of stress

Identification of other people as contributing to stress experienced in relation to living with diabetes included family and friends, and health care professionals. Four women identified family and friends as contributing to stress in relation to their diabetes – Carol, Pam, Lyn and Janice. In this section it is not the relationship with others which is seen as a source of stress, but the behaviour of other people in 'policing' their diabetes.

Both Carol and Pam disliked other people telling them what to do with regard to their diabetes care. Lynn disliked being interrupted by others when she was concentrating on her insulin injections. Janice identified her mother and husband as contributing to her stress:

What do I find stressful? People fussing over you, like my mother. My mother comes to stay. She fusses and she says 'have you done your test today?', and I say 'yes, leave me alone', you know. I've done it for 26 years; you know what mothers are like.

(Interview data Janice 429–433)

Six women identified health care professionals as a source of stress in relation to their diabetes – Carol, Janice, Josie, Joy, Carla, and Irene. Carol disliked professionals, as much

as other people, telling her what to do with regard to her diabetes care. Joy had previously experienced rudeness from health care professionals and described unacceptable waiting times in clinics. Irene described her dislike of clinic visits as dating back to childhood when she felt different to other children. Janice, Josie, and Carla all described impersonal interactions with health care professionals. Josie described herself as feeling '*like a number*' (Interview data Josie 670). Carla expressed the strongest perception of stress in relation to health care professionals. She expressed discomfort at the contradictory advice she was given to not let diabetes disrupt normal life, but then being told to look after herself in a better way. She expressed her suspicions that this was for the benefit of the health care professionals rather than for her and as a result of this she avoided contact with them and fended for herself in order to avoid conflict, and described herself as '*iatrophobic*' (Interview data Carla 1264):

I have the feeling as though it was a justification that you must have diabetes specialists and nurses because we need to justify our existence and I think this is the wrong approach. They ought to do something for me and my diabetes; they ought to do something for me so I can do something about my diabetes and sorting out how to achieve quality of life.

(Interview data Carla 1228–1233)

I'm really surprised because having had, not perfect control, by no means, nobody gets perfect control I don't believe that, but being not satisfied with myself, I'm still pleased, pleasantly surprised, how well and how fit I am. I hate to say this, but it's not thanks to the medics, because if anything they have stopped me getting there. I could have got there sooner, let's put it that way, and to have to struggle, that's not so nice, and they should be on your side, rather than having this almost confrontation, and that is sad.

(Interview data Carla 1284–1291)

7.4.2 Short term complications

Hypoglycaemia was the main short term complication referred to as a source of stress. This was unpredictable in its occurrence and manifested as a variety of symptoms affecting the nervous and endocrine systems (Chapter One). Marge had previously suffered major stress as a result of hypoglycaemia, but she stated that the frequency of attacks was improving. Conversely, Irene described hers as getting worse, with the potential for embarrassment when she was with other people. She found it difficult to maintain her blood glucose level within acceptable limits as this was compounded by the fact that she needed to pass urine frequently when her blood glucose levels were high, which she had found embarrassing when taking a long coach journey. Jane was concerned when driving, as she had previously suffered a hypoglycaemic coma during pregnancy.

7.4.3 Long term complications

Gina, Carmen, Pam, Joan, Paula and Joanne described the long term complications of diabetes, for example neuropathy, retinopathy, nephropathy and cardiovascular symptoms as stressful. The majority of women reported that it was the worry and anxiety of developing complications in the future that was stressful, rather than having the complication itself, but for Joan it was the presence, rather than the fear of, complications that she found stressful. Pam had come to realise that she had underestimated the seriousness of diabetes when she was initially diagnosed, and Gina was more aware of their importance as she got older, a sentiment also echoed by Carmen.

When you're younger you tend not to think about it so much, a bit like pensions.

When you're young you don't even think about them

(Interview data Gina 1657–1659)

I feel as if I need a more regular monitoring, so that if there is a problem I can have it dealt with straight away and hopefully..., it's a more preventative care really 'cos I think it's important.

(Interview data Gina 1668–1672)

Having to have a tighter time frame in your life, having to, you know, before you go to bed, 'do you want to have a snack?', and mostly I don't. Sometimes I don't just out of sheer bloody devilment. You think 'well for God's sake I don't want a rich tea biscuit, I'm not going to have one', but normally I just think 'Oh well, if it's better for my blood sugar, I'll go along with it', the frequent testing, it's just the regime it imposes on your life.

(Interview data Claire 876–884)

7.4.4 Self management issues

Self management issues are central to diabetes care, as it is the person with diabetes who manages the condition on a day to day basis. In the previous results chapters it has been demonstrated that planning is always required, leading to a loss of spontaneity (Section 5.2.4). Without meticulous planning, there is the potential for (usually) hypoglycaemia to occur in the short term, and other complications in the long term.

Self management issues described as stressful included those related to injections, blood glucose monitoring and dietary issues. When specifically asked about stress in relation to self-monitoring of diabetes, Lesley, Lynn and Josie all described injecting insulin and blood glucose monitoring as painful, Lesley to the extent that she was not willing to inject as advised by a health care professional.

I went to see the nurse before Christmas she said to do it in your stomach. Well I could do that for..., I tried it and I persevered but it hurt so much, and I thought 'I'm not having this, I'm not hurting myself every time I do this.

(Interview data Lesley 779–783)

The pain was quite awful, it was such a sting, you know, sometimes I get that here and it'll bleed and sometimes it'll really sting but it's a more bearable sting than it is there, so I just don't do it there any more. Sometimes I do it in my arms but they hurt as well.

(Interview data Lesley 794–799)

For Pam it was the timing of the injection in relation to meals that she found inflexible and always required planning, concerns also shared by Joanne. In relation to diet, Lynn described wanting a day off from dietary restrictions to eat foods that she enjoyed without it affecting her blood glucose control.

Some women identified a paradox between having to plan and constant uncertainty. Angela, Claire, Mandy, Carla and Janice referred to the stress they encountered in relation to this. Angela was unable to adjust her steroid dose used to control her rheumatoid arthritis as it had the potential to affect her blood glucose levels, illustrating the complexity of self management issues affecting control when multiple long term conditions are present. Janice and Mandy disliked always having to be prepared and then not knowing how they were going to feel on a day to day basis, and had experienced disruption to planned events as a result of diabetes. Carla found planning to prevent hypoglycaemia frustrating, as she described occasions where she had still been unable to drive due to hypoglycaemia in spite of her preparations. Claire described resenting the regime imposed upon her life by diabetes and her reaction to it.

The preceding section has examined the stressful impact of self management of diabetes. In some cases the reverse was indicated, and stress was reported as having an

impact on the self management of diabetes. Three quarters of the women reported that stress affected the way that they managed their diabetes. The responses of the sixteen women could broadly be divided into two categories, a) when changes in the self-management of diabetes were a deliberate behavioural response to stress and b) when it was due to forgetfulness or a subconscious response to the stress. Two women, Gina and Mandy reported a combination of both responses.

- a) Twelve women described deliberate behavioural responses to stress which affected the management of their diabetes, demonstrating that they were not passive recipients of care but actively managed (or ignored) it, depending upon their circumstances. Deliberate responses to stress broadly fell into categories where management of diabetes was affected adversely or in a positive way, and consisted of either omissions to self management, or deliberate potentially harmful actions. Carol, Lynn, Jane and Mandy all described being less likely to pay attention to their diabetes when they were experiencing stress. Carol reported that she was less likely to monitor her blood glucose as other demands took priority and Jane describes herself as putting her diabetes on '*the back burner*' (Interview data Jane 1100). Mandy described not eating a healthy diet and not exercising during periods of stress. Lynn reported being tired of managing her diabetes:

Oh sod it, forget it today, it won't make any difference.

(Interview data Lynn 1545–1546)

I'm fed up with this. I really am cheesed off.

(Interview data Lynn 1549–1550)

In terms of deliberately taking action which may be potentially harmful, Claire described challenging her diabetes in relation to food when she says '*bugger it; I will have this*' (Interview data Claire 1006). Both Lois and Janice referred to regretting their actions afterwards. Janice's account referred to administering a deliberate overdose of insulin to

herself, which she regretted when she woke up. Lois described '*cheating*' (Interview data Lois 1238) with regard to her diet.

Then I pay the price because then my blood sugar goes up and then I feel sick and I think 'well what a stupid thing to do, why did I do that?

(Interview data Lois 1239–1241)

Like Lynn, Judith described deliberate actions which were both helpful to the management of her diabetes when she was stressed, such as adjusting her insulin dose where necessary. However, she also described potentially harmful actions such as comfort eating. This again suggests the notion of a cyclical outcome of stress and diabetes, with the need for adjusting the insulin dose resulting from intake of additional carbohydrate as a response to stress.

Four other women referred to deliberate responses to stress in terms of self management which had the potential to affect diabetes in a positive way. Gina, Angela and Marge all described reactive responses, where blood glucose monitoring was increased and insulin adjusted as a reaction to a change in blood glucose levels at times of stress. Annette was the only woman to describe a proactive response to stress, by adjusting her insulin levels in advance of a known stressful event occurring.

- b) Six women reported subconscious responses to stress in terms of forgetfulness, which affected the management of their diabetes. Carla described herself as being '*not so attentive simply because there are lots of other things*' (Interview data Carla 1172). All of the other women – Liz, Josie, Gina, Irene and Mandy referred to forgetfulness and making mistakes in relation to blood glucose monitoring and insulin injections. Both Josie and Irene commented that this was due to a lack of routine at times of stress, whereas Liz attributed this to being very tired at the end of the day. Gina reported that her forgetfulness led to her then having to take deliberate action in order to rectify the situation, when she accidentally gave herself two injections of insulin one morning.

The previous sections of this chapter have examined the nature of the experience of stress, the relationship between stress and diabetes, and diabetes related stress as reported in the interview and survey data. The section relating to self management issues underscores the complexity between the demands of daily life and managing diabetes, with the aim of achieving control over their diabetes and lives. However, the desire to achieve control may conflict with the reality of being able to achieve this. Also, the definition of the concept of control may differ between health care professionals and the women who are living with diabetes on a daily basis, and conflict may ensue. This conflict is discussed within the following section which examines the theme of *maintaining control*.

7.5 Maintaining control

Control is central to diabetes care, both to health care professionals and to the person with diabetes. However, understandings and meanings of the word may not be shared by the two groups. For this group of women with diabetes, meanings of control were more complex, with both physical and psychosocial elements being described, alongside indications that control was not a static, but a dynamic, concept. Control may be described as physical, psychological or social, and elements of all or some of these may be relevant to women with diabetes managing their lives.

7.5.1 Being in charge

Being in control was associated with being in charge of both diabetes and life in general. Most of the women interviewed identified themselves as being exclusively in charge of their diabetes (87% n=20). Carla referred to fate being in charge of her diabetes, as well as herself, in the sense that planning for events was not always enough, and things like the weather could affect her diabetes in spite of her organisational skills. Carmen also

referred to the fact that although she aimed to take control of her diabetes, ultimately she was aware that she may not be able to do so.

Whilst I've always said that I'm in control, I do know ultimately that maybe I'm not, because it's almost impossible to be able to be sure of what's actually happening in your body.

(Interview data Carmen 857–861)

Judith referred to her daughter at times being in charge of her diabetes during emergency situations such as hypoglycaemia, when she was unable to care for herself. Only one woman, Lynn, felt that the doctor at the clinic was solely in charge, although she qualified this during her interview by saying that she was in charge on a day to day basis. She saw the consultant as being in charge of the clinic and staff; therefore he was in charge of everything to do with her diabetes, although she only saw him infrequently.

Control is something or someone that's in charge. Dr X is in charge. He's in control of the clinic, and he's in charge.

(Interview data Lynn 315)

At the end of the day it's me that has to take the insulin, it's me that has to get up off the floor if I have a hypo and it's me that has to live every day. Dr X isn't there specifically for me, he's there for hundreds of others.

(Interview data Lynn 306–309)

Half of the women interviewed equated control with ownership of diabetes and their bodies. There was a sense that their bodies belonged to them and it was their right and responsibility to control what happened within it. They were unwilling to relinquish that control to other people, whether they were relatives or health care professionals.

I don't think I can really give control to anybody else, because it's my life, why should they have that? It's me, you know? It's my problem.

(Interview data Josie 386–388)

However, there were occasions when some women requested help with their diabetes control from external sources, and felt that there was a sense of blame and that the responsibility was handed back to them inappropriately. Lois described a situation when she was told that the reason for her diabetes being poorly controlled was due to her mismanagement, when in fact it was due to commencing human insulin when she had previously been taking animal insulin (Chapter 5 – Footnote 1) She had previously had a good experience of feeling that there was a partnership between herself and health care professional controlling her diabetes, during pregnancy. Carmen alluded to the fact that she did not feel able to be in control by herself, but needed access to a good support system, but when she needed it, rather than being told when. Lynn referred to being told that she should be more in control and be more methodical and less '*lax a daisy*' (Interview data Lynn 233) in her approach to managing her diabetes. Irene recalled being told that diabetes was her responsibility as a child, and the effect that had remained with her after having diabetes for forty seven years. Joanne reported feeling upset because of the response of a doctor when she was worried about the onset of long term complications.

So I went to the doctor and he said 'you're a diabetic. What do you expect, tighten up your control.

(Interview data Joanne 813–815)

A desire was also expressed by the women that they should be in charge of their diabetes and not vice versa. It was when the diabetes was perceived as being in charge, that the women that reported that they did not feel in control, and there was a sense of determination that this should not occur.

Controlling your diabetes means making sure that it works for you and you're not a slave to it.

(Interview data Lesley 108–110)

This view suggests that power is integral to maintaining control, something Claire referred to as '*personal power and agency*' (Interview data Claire 231). She clarified this as meaning an ability to take decisions that she felt were right for her at the time, without having to refer to anyone else for legitimisation and maintaining a sense of self, as did Gina. Joy reported a similar view, when she talked about having the right to choose to be out of control if she wanted to, a concept that can be difficult for others (particularly practitioners) to understand. Carla was concerned about the safety aspects of keeping diabetes in control and referred to '*non dangerous limits*' (Interview data Carla 568). She spoke about her fear of dying as a result of hypoglycaemia occurring as a result of not being in control, but also strove to maintain an acceptable quality of life. Gina also referred to the concept of power in relation to control:

I feel I have the power of my own destiny if you like. If I'm sensible and I'm good, then I'm going to be OK. If I'm silly and I do things that I shouldn't do, then I'm not going to be OK It's the same thing really, it's just the power to make things happen the way you want them too I suppose.

(Interview data Gina 1032–108)

In the above quote Gina refers to being '*good*'. Conversely, some women referred to being '*naughty*' (Interview data Lesley 801, Gina 529, Pam 217, Angela 883, Lynn 1828, Judith 1107, Marge 276). This implies a sense of blame or guilt, and not adhering to a set of rules. Pam referred to this in the context of eating more than she felt that she should have done and referred to this as being her own '*fault*' (Interview data Pam 667). Angela also reported being '*naughty*', but not in the sense of being at fault, when she stated: '*You've got to live and enjoy yourself, so you bend the rules occasionally*' (Interview data Angela 997–990).

These women were positioning themselves in relation to others who are regulating their behaviour. Rules are seen as external to themselves and are imposed by others with less experiential knowledge.

7.5.2 Physical control

Control of diabetes was generally seen to relate to glycaemic control and maintenance of optimum blood glucose levels to avoid the development of long and short term complications of diabetes such as hypoglycaemia, ketoacidosis and permanent vascular complications. Blood glucose control is the measure utilized by the dominant medical discourse to assess success in managing diabetes. However, this may not accord with the constructions of control relevant to the lives of the women living with diabetes. In many cases it was the feeling of being '*normal*' that was of importance and this equated with feeling well and not having hypoglycaemic attacks. Lois described this as '*I could be very flippant and say get to the end of the day without falling over*' (Interview data Lois 812). For many of the women, maintaining the status quo was an achievement in relation to controlling their diabetes.

I actually feel in control when I forget about my diabetes. If I can forget about it it means that it is not intruding in some way, by being high or low, and that means, I imagine I feel normal, for want of a better word. Being in control gives me the opportunity to be what I call "normal".

(Interview data Annette 773–781)

Some women preferred the reassurance of knowing that their blood glucose levels were within acceptable limits and Carol referred to keeping her blood glucose level below 15 and above 2 as being her measure of success. She was aware that her health care professionals would want a different level of blood glucose (between 4 and 7mmols per litre). However, her view was that she had ownership of her diabetes.

It's mine to control and indeed mine to listen to what the doctor says and decide whether I want to follow it or not, which is one reason why I hate being in hospital because they take the control away from you.

(Interview data Carol 1640–1644)

Loss of physical control may lead to loss of other forms of control as described below. Hospitalisation may result in loss of physical control as the woman may be unable to attend to her own physical needs in relation to diabetes. She may not have access to equipment, or be able to control administration of medicine. Women's reports of attempts to gain control include descriptions of access to the outside world by using a telephone being denied, and removing intravenous insulin infusions because the woman knew that the amount given was dangerous (Section 6.2.2).

These incidents were illustrations of where the power and control resided with the medical hierarchy, but the knowledge remained with the woman. Such events were reported as leading to a reluctance to be hospitalized on the part of the women involved. It was in the area of maintaining glycaemic control that women described conflict with health care professionals. Conflict with health care professionals was associated with patient roles adopted by the women which were at odds with their adult autonomous roles within their social context. Words used were '*argue*' (Interview data Marge 974), '*struggle*' (Interview data Carol 958), '*confrontation*' (Interview data Carla 1291), '*fight*' (Interview data Lynn 623) and '*threaten*' (Interview data Tanya 1041). Lynn included the following image of a nurse within her journal (Figure 7.1). She described her initial encounter with a new nurse at the surgery. Her response was to leave as soon as possible and to '*forget*' to attend for the next appointment – a missed opportunity for both the health care professional and the woman with diabetes. Carla recounted that she was pleased with how well she had managed to remain in control of her diabetes, but that it was in spite of health care professionals, not because of them, and how she viewed their relationship and her regret about its nature. The outcome of this was that

she felt 'threatened' (Interview data Carla 591) when she went for clinic appointments and did not want to attend as she felt 'aggravation and annoyance' (Interview data Carla 594) and was always deliberately late.

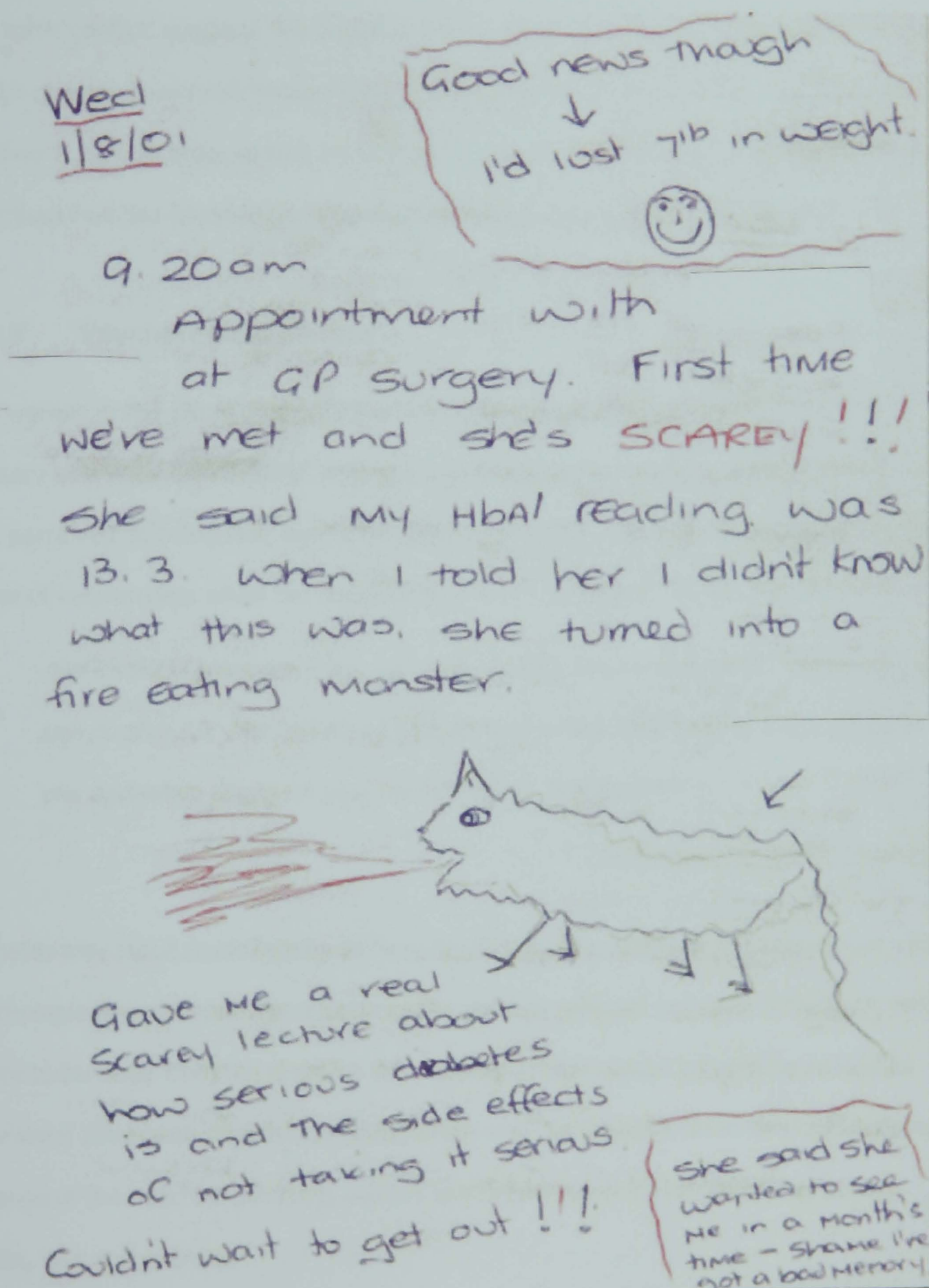


Figure 7.1 Entry from Lynn's journal.

To have to struggle, that's not so nice, and they should be on your side, rather than having this almost confrontation and that is sad.

(Interview data Carla 1290–1292)

The term 'conflict' suggests the presence of an adversary. Adversaries described included health care professionals (Section 5.2.2), diabetes itself (Section 6.2.3), and other people (Section 5.2.2). In order to face an adversary weapons are needed. Weapons that women described included knowledge, support from others, advice and information.

7.5.3 Psychological control

The women in this study often defined control in psychological terms as a sense of mastery over their own destiny. Negative psychological reactions ensued when control was perceived as being lost, due to the effects of diabetes. Judith referred to fear and a sense of helplessness when her diabetes was out of control due to an infection:

And it's frightening when it's out of control big time because there's nothing you can do about it. I've laid down here on that settee thinking that I was going to die, and when you're on your own it's hard. You know?

(Interview data Judith 1546–1549)

Diabetes may result in limitations as have been discussed earlier in this chapter, to which psychological adjustments have to be made. Women referred to a lack of freedom, and a desire to be away from the diabetes for a period of time. Janice referred to herself as 'free spirit' (Interview data Janice 1026) which was not possible when she had diabetes because of the need for planning, routine and organisation in relation to monitoring, insulin, diet and exercise.

I'd just like to get away, and just for a couple of days get away from having to use ointments, or tablets, or insulin.

(Interview data Lynn 265–267)

Lynn reported feeling that she was being 'ruled by a piece of paper (Interview data Lynn 257), and not being able to live the life she wished to live, indicating a loss of agency. She was referring to guidelines given to her by the hospital which she regarded as rules. Irene also stated that she was never able to completely relax. Tanya referred to feeling insecure and nervous if she felt that she was not in control of her diabetes. Claire described a sense of loss and feeling restricted by having to stop what she was doing in order to eat to avoid hypoglycaemia and that she had lost some of the spontaneity in her life. She was also forced to face the fact that there had been a loss of her previous good health status, and that this would more than likely have long term effects and that at some point she would need to give control of her life over to other people at an earlier stage than she had previously anticipated. To her, retaining a sense of self was of paramount importance.

I can't be somebody else and I'm certainly not going to be somebody else because of this condition.

(Interview data Claire 788–789)

Being worried about the future and the development of complications was a major issue but women often made a conscious decision to keep blood glucose control outside of optimal limits in medical terms to enable them to function within the needs of their lifestyle. Immediate issues took priority over long term glycaemic control. However, fear of the development of long term complications was at the back of their minds, together with strategies about their management, including, at the most extreme, suicide – the ultimate control (Section 6.2.1). Luck and fate was seen to play a part in whether the complications developed suggesting an avoidable lack of responsibility, but conversely guilt and blame were also seen to be an influence where responsibility lay with the woman for her own destiny (Section 4.3.1). The issue of conflict in relation to blood glucose levels was raised by Joanne, when she referred to blood glucose as an 'enemy'.

You imagine the sugar in you as an enemy sort of clawing at you.

(Interview data Joanne 587)

Yes, high blood sugar is an enemy, yes. Strong word, but it's doing long term damage if it stays like that.

(Interview data Joanne 589–591)

A fear of losing control, especially in relation to hypoglycaemic attacks both in a physical and psychological sense was vocalised, and this often resulted in running blood glucose levels high to avoid this, rather than long term complications, although the effects of the latter could be more devastating in the long term. Many women referred to the presence of hypoglycaemic attacks as an indicator that they were not in control of their diabetes, and Lyn again introduced the issue of conflict when she referred to them as *'fights with the kitchen cupboard or floor'* (Interview data Lynn 624). Carol referred to the inability to control her whole body following a hypoglycaemic attack and not be able to move and the resulting fear. Lois stated that her greatest fear was becoming hypoglycaemic while driving and that she would *'never let that happen'* (Interview data Lois 1147). Carla referred to her view that *'every hypo is a terrible failure'* (Interview data Carla 624–625).

7.5.4 Social control

This aspect of control refers to the woman feeling that she is in control of her social and work situation and that she is not controlled by it, or by other people with whom she has a relationship. For Claire, her work and social roles as a lecturer and carer for her elderly mother were of primary importance. She found it particularly difficult to deal with her experience that in spite of careful planning to enable her to function in these roles, the unpredictability of her diabetes sometimes interfered with this, and she stated that she did not want any external control of her diabetes. Stress was a barrier to control in this situation and the results of it may have affected her social identity and management of situations. Avoidance of embarrassing hypos was seen as a priority by many of the

women who were in paid employment and taking social control depended upon the amount of power that a woman had in a given situation. Josie hid her hypoglycaemic attacks from her work colleagues and managers by going to the ladies cloakroom to deal with them in private. Marge worked mainly from home, so her diabetes remained largely private and she stated that she was able to '*push it on to the back burner*' (Interview data Marge 946–947), and was able to live a life that she considered to be worthwhile and a contribution to the community within which she lived. However, the conflict for her was related to the fact that her husband wanted to take control of the management of her diabetes in terms of diet and administering her insulin, which she was not prepared for him to do, resulting in a power struggle between them. She did not want him to know that she was taking part in this research study as she felt that he would want to take control of the interview. Annette was upset as she no longer felt that she was able to control her diabetes independently, particularly when she was hypoglycaemic.

The control has now passed to my husband and my children after him, and to me it feels rather like offloading my responsibilities onto them, which I find difficult to cope with.

(Interview data Annette 1543–1547)

Strategies that were utilized by other people such as health care professionals or friends/relatives to take control were use of power within the medical system, surveillance in the form of monitoring blood glucose levels and imposing restrictions especially in dietary terms. Strategies that were utilised by the women included confronting the health care professionals, falsifying results of home blood glucose monitoring and '*cheating*' (Interview data Judith 2276) on their diet. As Annette stated:

It's my decision; it has to be me that gets it wrong. It's all my doing.

(Interview data Annette 823–824)

This chapter has examined and reported on results relating to stress and diabetes from survey (LWDQ) and interview/journal data. The overarching theme of maintaining control has been examined in physical, psychological and social terms. The concept of conflict in relation to diabetes itself, health care professionals and other people was embedded within this overarching theme due to the intertwined and interlinked nature of control and conflict.

Although health care professionals have some control within the health context of the women's lives and women may be perceived as having no choice about being part of a medical system of care, the balance of power is evened out as women are likely to have a greater degree of control in their social and cultural context of daily living. If there is a mismatch between the two, when the two worlds meet there is the potential for conflict to occur. The psychosocial world and the biomedical world may conflict with each other. Health care professionals adopt a biomedical focus which is concerned with correcting a physiological abnormality – an inability for the pancreas to produce sufficient insulin. To a large extent, this focus ignores psychological and social factors. For the women living their lives with this condition, it is these additional factors which shape the management of their lives with diabetes.

CHAPTER 8

Putting it into perspective – Discussion

This thesis has been concerned with the experiences of women in midlife living with diabetes, particularly in relation to the concept of stress. A sequential exploratory mixed methods approach has been adopted to explore this, within a feminist empowerment theoretical framework. This discussion chapter is divided into three main sections considering firstly the research findings and their relationship to existing literature, and how this research makes a contribution to the field of diabetes care. The subsequent section will explore a conceptual framework relating to the process of living with stress and diabetes. This will be followed by a reflexive section examining the research process itself, including a consideration of my role as both the researcher and a clinician, and a critical review of how the research methods have answered the following research questions.

- What do women describe as stressful in relation to their insulin treated diabetes?
- What impact do these stressors have on women's lives?
- How do women with insulin treated diabetes interpret and manage their lives?

A concluding chapter will reflect upon the implications of the thesis for diabetes knowledge and its application to clinical practice, dissemination of the research findings, the limitations of the current research, and the potential for future research.

8.1 Research findings

Using an IPA approach to analysis, the main findings of this thesis are that for this group of women living with diabetes in midlife, diabetes is seen as a nuisance. There are stressors in both daily life and also at times of crisis associated with diabetes which have the potential to both affect, and be affected by, diabetes. Experiencing stress and maintaining control are overarching themes in relation to living with diabetes. A cyclical relationship, with the potential for the development of a spiralling relationship, between stress and diabetes is suggested.

Previous approaches to researching diabetes have taken a largely quantitative view that is not gender-specific, with few studies examining the lived experience of women with insulin treated diabetes (Agrawal and Pandey, 1998; Anderson and Bury, 1988; Woods et al., 1993). The majority of work that is gender-specific is concerned with reproductive functions in relation to diabetes (CEMACH, 2005; Linn and Bretzel, 1997) or eating disorders (Grant, 1991; Polonsky and Anderson, 1995; Rapaport et al., 1996). There is however some emerging literature in relation to Type 2 diabetes although not specifically focussed on women (Anderson et al., 1995; Delahanty et al., 2007; Gonzalez et al., 2008; Koch et al., 1999; Lin et al., 2004; Lloyd et al., 2008). Like Anderson's work, this study has also concluded that living with diabetes is a multifaceted phenomenon, which takes place in the 'mediating circumstances' of women's lives, that is the social context of interwoven roles and relationships.

Interpretative Phenomenological Analysis (Smith, 1994; Smith et al., 1999; Smith et al., 2009) of the qualitative data identified the research themes illustrated in Figure 3.2. The two overarching and interlinked themes of *experiencing stress* and *maintaining control* are at the top of the hierarchy, and are underpinned by the three major themes of *diabetes as a nuisance*, *diabetes in daily life*, and *diabetes during times of crisis*. These themes run throughout the data chapters and are central to the thesis as a whole. Each of these four themes will be considered below.

8.1.1 Experiencing stress and maintaining control

An examination of the literature in relation to stress and diabetes suggests that stress is a complex concept to define as it is dependant upon the subjective experience of each individual (Levi, 1995; Selye, 1956). In spite of this, the majority of previous studies have adopted a quantitative approach to its exploration, and have largely ignored personal accounts. To my knowledge, based on extensive literature searching, this research is the first that specifically examines the experience of stress and diabetes in women in midlife. This study has identified that stress was an important issue for this group of women, as has been discussed in Chapter 7. Stress was described as a complex dynamic concept, which was difficult to define, and was related to expectations of the self and others. It was described either as an event in itself or as a response to an event in physical, emotional or behavioural terms. Some of the physical effects described by Selye (1956), in relation to the effects of adrenaline and the effect of stress on the immune system leading to symptoms such as anxiety and headaches, were identified by the women interviewed. The description of these symptoms was often combined with the more subjective and environmental elements of stress as described by Kasl (1995). These included descriptions of stress responses that were specific within a particular relationship such as Judith and her teenage daughter, or within a specific context such as Joy and her financial problems. The majority of women perceived there to be a relationship between stress and diabetes in relation to blood glucose control (Section 7.2) in that stress affected their diabetes and the way in which it was managed, either directly or indirectly. This supports Lloyd et al's work (1999) which found that positive stress was related to improved glycaemic control (i.e. reduced HbA1c), and that negative stress led to poorer glycaemic control. However, results from previous studies have been diverse, and at times contradictory. Lustman et al. (1981) demonstrated that whilst acute stress in people with diabetes appeared to cause destabilization, there was no convincing evidence that acute stress caused hyperglycaemia. The change in glycaemic control could be in either direction, for reasons which are not fully understood (Gonder-Frederick et al. 1990), and

indeed this was clearly indicated by the women interviewed. Although the majority referred to their blood glucose levels being high at times of stress, some reported hypoglycaemia and others as it fluctuating between high and low levels. This suggests a degree of unpredictability which could be argued to further increase stress levels.

In this thesis two sources of reported stress were the experiences of hypoglycaemia, and the women's relationships with health care professionals. Hypoglycaemia was identified as the main sources of stress in terms of the short term complications of diabetes and this accords with Wild et al's (2007) findings in their critical review of the literature on fear of hypoglycaemia in diabetes. They found that fear of hypoglycaemia was a widespread phenomenon, which had the potential to result in considerable anxiety. There was also the potential for a negative impact on diabetes management and control, as well as negative emotional, social and behavioural consequences. They state in their conclusion that people with diabetes are attempting to balance the need to avoid hypoglycaemia with the desire to prevent the long term complications of diabetes. This thesis adds a third dimension to this balancing act, that of the women striving to maintain their roles within their social contexts. For Annette, this meant maintaining a professional identity in her job which involved meeting new people, whilst also attempting to ensure her blood glucose levels remained at optimum level.

Health care professionals being identified as a source of stress can be considered in the context of the conflicting perception of what constitutes the concept of control in diabetes care between health care professionals and the women taking part in this research study. Control is central to diabetes care for both groups and being in control has been identified as an active attempt not to allow diabetes to restrict lifestyles (Kelleher, 1988). However, for many health care professionals the emphasis is on the control of the levels of blood glucose, with the aim of reducing the likelihood of the development of long term complications in later life. For the women interviewed, the concept of control related to being in charge of their lives on a daily basis and within their own particular social context. The vast majority of the women stated that this was the

case and they viewed themselves as having the sole responsibility for this psychosocial control and agency. However, there was a contrast between the control they experienced within their daily lives, and that experienced within their relationships with health care professionals and conflict imagery was used in descriptions of such relationships. There was often a dislocation between the ideal images of the health professional's role and the reality encountered. The encounters described suggested a process of infantilization within a patriarchal relationship, a role which was at odds with the women's autonomous roles within their social context. This was particularly apparent during periods of hospitalization, where control over mechanisms usually used to maintain both biomedical and psychosocial control were removed (Section 6.2.2). This relationship can be examined in the context of the contrast between the compliance and empowerment models of care (Lloyd et al., 2008; Lloyd and Skinner, 2009). Compliance is a restrictive model of care where the power lies with the health care professional with precedence being given to learned medical knowledge, based upon scientific principles, and can be costly in psychosocial terms if compliance requires limitations to life and loss of spontaneity on a daily basis (Kelleher, 1988). Due to the restrictiveness of this model, it invites behaviour which is viewed as non-compliant by the medical hierarchy, within a culture of blame (Trostle, 1988). However, this research has identified that the motivation for such actions are not the result of what could be interpreted as rebelliousness for its own sake, but an attempt on the women's part to maintain control of situations in their everyday lives and to avoid disruption in either the short or the long term (Bury, 1982). In an approach to care which embraces the principles of empowerment (Anderson, 1995b; Anderson, 1996; Anderson and Funnell, 2010; Anderson et al., 2000; Funnell and Anderson, 1991; Gibson, 1991; Rappaport, 1984), these actions would be accepted as an integral part of the philosophy of care, where the power balance is at least more shared between the patient and the professional, and at best lies with the patient. Legitimization of actions is not required by the professional, as the process of goal setting is a shared one, utilising both medical and experiential knowledge. This research has highlighted the split between the

rhetoric and reality of empowerment in diabetes care, which has been described as underpinning current diabetes policy within the United Kingdom (Begum and Por, 2010; DOH, 2001, 2004, 2010; Hicks, 2010). In terms of the Szasz and Hollender (1956) model of interaction, the majority of the women vocalised that they desired behaviour consistent with the mutual participation model with adult/adult relationships, whereas the reality was often the activity/passivity (child/adult) relationship.

The above findings illustrate that the women in this study managed their diabetes for the most part within a social context, with occasional contact with health care professionals. However, although contact may have been infrequent, the medical experiences were intense particularly if they occurred within an in-patient hospital setting where women felt little control over their situation or diabetes and reported incidents which were bordering upon the abusive.

Within the medical setting, the dominant medical discourse was seen to take priority over the women's subjugated and experiential knowledge. A compliance model of care was adopted, not only by members of the medical profession, but also by members of other professional groups who could themselves be interpreted as belonging to other oppressed groups in feminist terms, such as nurses or other allied health professionals. This could be interpreted either as intentional collusion by virtue of being members of the dominant health care system, or because they viewed their own roles as being suppressed either by this system or individuals within it.

In terms of the experience of stress within the social setting, the women's own needs in terms of diabetes often took a secondary place to the needs of others in their roles as worker, partner, mother and carer. People with whom they had a social, personal or collegiate relationship also adopted the hegemonic medical discourse, thereby forcing the women into a submissive position of a passive, medicalized and infantilized patient, as opposed to that of an active and responsible member of society.

These findings support the feminist empowerment theoretical approach adopted within this thesis, and highlight that there remains a need to make these experiences visible and voices of the women heard, in both the medical and lay arena (see Chapter 9).

8.1.2 Diabetes as nuisance

One of the major themes that emerged from the data analysis was that diabetes was a nuisance, rather than an illness. Diabetes as a nuisance is defined in a range of ways as indicated in Chapter 4; as an obstacle, pain, difficulty, bother and irritation. There is little published literature relating to the experience of illness as a nuisance. Although Shu-Ki Tse's (Shu-Ki Tse, 1999) study is entitled '*the nuisance factor*' in relation to long term psychiatric disabilities it actually examines the relationship between daily stresses and coping behaviours using a quantitative approach, and does not examine the concept of nuisance in relation to long term conditions. Other studies of nuisance are related to issues such as parasitical disease (Franck, 2003; Nacher, 2002); ailments which may be considered as a minor nuisance such as ankle sprain, menstruation, hearing loss, snoring or minor sexually transmitted diseases, but may have far reaching effects in terms of symptoms (Jarvis, 2003; Kirkendall, 2003; Rezen, 2005; Strote, 2004; Thomas, 2000). Although these are relatively minor conditions in terms of the long term effects, the symptoms may be problematic and uncomfortable, but for a limited period of time. Some may also affect others such as snoring or sexually transmitted diseases. This is similar to other perspectives on nuisance which relate to nuisance as perceived by others, rather than experiential perception of nuisance by the person concerned. Examples include continence care, people with dementia, and caring for those with mental health needs (Godin, 2000; Roger, 2007; St John, 2002). With diabetes, although there is the potential for the development of serious long term complications affecting major organs of the body, many of the women did not experience symptoms for the majority of the time. It was the process of managing the diabetes that was sometimes described as problematic rather than diabetes itself. When symptoms occurred as a result of diabetes such as

hypoglycaemia, the degree of nuisance was substantial, hence the need for a continuum to account for the degree of nuisance (Section 4.3). The single article found with regard to nuisance in relation to a woman's experience of living with a long term condition (Raynaud's disease), consisted of a single page descriptive case history (Roush, 2005), strongly suggesting the need for further research in this area. This thesis has contributed to this limited body of knowledge by making an original contribution in this field and increasing our understanding of the experiences of women with diabetes and how they view their condition, particularly in relation to nuisance.

As discussed in Section 4.2, poetic representation of data was used to represent the findings of the theme of diabetes as a nuisance. The criteria for the success of the poetic representation were identified as Richardson's (2000) criteria for use with Creative Analytical Practices (CAP) which have been adopted for use in this research where a scientific and creative approach have been mixed together. These criteria are substantive contribution (how far the results contribute to understanding), aesthetic merit (are interpretative responses invited?), reflexivity, impact (is there an emotional and/or intellectual effect?) and expression of a reality (is it a credible account?).

The poem was not returned to the women who took part of the research, as I was concerned for the emotional impact it may have had for those who were at the '*bit of a nuisance*' end of the continuum, and who may never progress to the '*bloody nuisance*' end. However, I have presented the poem at local, national and international conferences, to both lay and professional audiences. The resulting reaction from both those with diabetes themselves, relatives of those with diabetes and those suffering from other conditions has led me to assess that the poetic representation fulfilled the above criteria. Such comments related to the fact that it captured the essence of the experience of living with diabetes, and one man whose wife had recently died from the long term complications of diabetes was clearly impacted upon emotionally. From a reflexive point of view, as defined in Section 3.1.3, the co construction of the poem enabled the women who took part in the study to be actively involved in the definition of their own experience

as the poetic representation was composed entirely of their own words. A further discussion of the judgement criteria employed within this thesis can be found in Section 8.2.3.

Although the concept of diabetes as a nuisance is a new one, hassles and stressful life events in relation to diabetes are not, although the literature is limited. The following two sections will discuss the literature in relation to the two major themes of *diabetes in everyday life* and *diabetes at times of crisis*.

8.1.3 Diabetes in daily life

This major theme, discussed in Chapter 5, reflects the complexity of managing diabetes in the context of daily life and the data was collected in the context of the women's current experience. The women interviewed all led active full lives, with the exception of one woman who was struggling with the long term complications of diabetes. The experience of women managing daily life with diabetes centred on work/study activities, social activities, relationships, and domestic and social roles. Although these activities may be common to many women, including those without diabetes, the difference for women with diabetes was that they also had to manage the activities associated with diabetes such as monitoring blood glucose levels and injecting insulin. This required a constant state of awareness and planning, when the outcome could still be uncertain as in the case of hypoglycaemia. When diabetes seriously interfered with their lifestyle such as them becoming hypoglycaemic, role reversal could occur between the mother and her child, with the child taking responsibility for the mother's well being as in the case of Annette's daughter who found her mother hypoglycaemic in the bath. The equality within the relationship of the woman and her partner could also be challenged at these times.

Managing diabetes in daily life can be perceived as equating to hassles as described by Kanner et al. (1981, p. 3). They defined hassles as '*irritating, frustrating, distressing demands that to some extent characterise everyday transactions with the*

environment. They include annoying practical problems such as losing things or traffic jams and fortuitous occurrences such as inclement weather, as well as arguments, disappointments, and financial and family concerns'. Their Hassles Scale consists of 117 items on a Likert-type scale relating to the frequency of such hassles. Although they are not diabetes-specific hassles, many relate to the experiences reported by the women in this study as being stressful and which affected their diabetes. Examples relate to the health of another family member as described by Lynn in relation to her brother and parents, concerns about owing money as described by Joy, having too many responsibilities which Carla alluded to in relation to her work and home life, and the weather which Lois described as affecting her diabetes control.

This study has demonstrated the difficulties of maintaining multiple roles within the context of managing diabetes in daily life. All of the women in the study had multiple roles, some to a greater extent than others. Packard et al's (1991) discussion of disease related demands strongly resonates with the experiences of the women in this study. Packard et al. have suggested that the struggle of psychosocial adjustment persists long after the initial diagnosis and treatment phases in long term conditions, and this is evident in this thesis as many of the women reporting stressful experiences had been diagnosed for many years, forty seven in the case of Irene. Packard et al. (p. 436) refer to chronic illness as '*a dynamic process of patterned stressful events and experiences*'. They suggest that sources of stress are complex, multidimensional and embedded in everyday life, as also evidenced in this study. Their longitudinal study of stressful illness – related to experiences of women with non-metastatic breast cancer, diabetes or fibrocystic breast disease – identified the on going demands of chronic illness. These demands were categorised into disease related demands, personal disruption demands and environmental demands. Disease related demands refers to the direct effects of the disease. In this thesis participants recounted experiences directly attributed to diabetes, as in the case of hypo and hyperglycaemia. Carla referred to herself as being '*medicalised*' and '*iatrogenic*', a term coined by Illich (1975). Packard's (Packard et al., 1991) personal

disruption demands, refers to changes in the life course as a result of the disease and relate to the work of Bury on biographical disruption in terms of unmet personal expectations (Bury, 1982). In this study personal disruption demands included changes in the perception of self in relation to body image as described by Lynn with regard to her weight and when she hinted at having an eating disorder. Changes in lifestyle were also implicated, for example in relation to injecting in social situations as described by Angela and Paula. Environmental demands refers to events that occur in relation to the social context, and how the woman is perceived within that environment. For Janice and Joy, being seen as somehow different was too demanding, and they made the decision to leave their employment. Management of social networks required careful organization by Claire, to avoid embarrassing incidents when in public. Packard et al's results imply that the primary sources of stress experienced by the women in their study are not necessarily due to the direct effect of the disease itself on physical and psychosocial wellbeing, but rather the contextual experiences of an intrapersonal and environmental nature. The findings in this thesis are largely in agreement with this. Although hypo and hyperglycaemia are due to the effects of diabetes, it is the contextual significance of these that the women referred to in this thesis, rather than the physiological effects themselves. It can be argued that the concept of nuisance in diabetes experience can be conceptualized as an additional demand of a long term condition, similar to those identified by Packard et al. (1991).

The management of chronic illness in general has been described by Strauss (1985), using a grounded theory approach who divided this management into categories relating to daily living and medicalisation, both of which relate to diabetes as reported by the women in this study. Managing self-care was described by the women in relation to their descriptions of a typical day in this study, in which their activities of daily living were intertwined with self-management behaviour. In terms of diabetes, controlling symptoms relates to the management of blood glucose levels, in both the short and the long term, to avoid the development of the long term conditions of diabetes, and acute episodes of

hypo and hyperglycaemia. Managing the course of the illness as described by Strauss is also related to the avoidance of the development of long term conditions, as described by Joy. Strauss described social isolation, clinical environments and normalising life as outcomes of living with a long term condition. For the majority of the women in the study social isolation was not an issue, the exception to this being Joan who was largely confined to the house because of debilitation due to the development of long term complications, and was unable to carry out many of her previous roles as a result. Issues in relation to clinical environments were reported in relation to outpatient interactions with health care professionals, such as Judith's account of her discomfort in outpatients and also inpatient stays as described by Angela during her surgery for another chronic condition. However, it was diabetes related, rather than surgical issues that caused her the most distress as described in and related to issues of control. Whilst the approach taken in this thesis is that of IPA rather than grounded theory, the mixed methods approach allowed for examination of issues from differing perspectives, enabling a greater understanding of the complexity of living with a long term condition.

Strauss' concept of normalising life is closely aligned to Royer's (1998) account of normalising behaviour. '*Survival tactics*' are described by Royer (1998, p. xi), and these are the positive choices made to behave in a way that is defined as normal by society. This is closely related to adapting to diabetes or '*normalizing*' as described by Kelleher (1988, p. 147) where changes were made to lifestyle to accommodate diabetes, and a revised way of life was accepted. Examples given in this study include eating in the same way as everyone else in Lynn's '*sod it club*'. Some women chose to keep their diabetes hidden in a secretive way in the work environment and Josie described hiding in the cloakroom when hypoglycaemic, in an effort to appear what was defined as 'normal' within her social context and to avoid taking on a role defined by diabetes in public. Other behaviours included keeping blood glucose levels higher than the values recommended by health care professionals to avoid hypoglycaemia in public situations, as described by Annette in relation to her working environment. These behaviours may not coincide with

notions of 'compliance' or 'adherence' as described in Sections 2.2 and 2.3, and as defined by health care professionals, but were examples of the women taking a form of subversive control within a situation that can be described as oppressed in feminist terms. Interactions with health care professionals may become a source of stress in themselves and a conflict situation may occur, which Lynn described in her journal in relation to a nurse at her diabetes clinic. The end result was that she did not intend to attend future appointments – a missed opportunity for education, screening or support if the interaction had been a mutually respectful one. Similarly, Carla reported being deliberately late for her appointments as she did not wish to attend. Marge left the clinic system for some time for similar reasons. However, a sense of disruption to the sense of self may be avoided (Bury, 1982). This was reiterated by Carla in her assertion that she was not defined by her condition in that she was a '*diabetic*', but '*Carla who happened to have diabetes*'. Tanya continued in her role as a director of her own company and Gina gained several promotions and a higher degree in spite of having had diabetes for twenty years. In contrast, others made major changes to their planned career trajectory as a result of having diabetes. Mandy left a senior position in the local authority due to difficulties with hypoglycaemia and mental health issues, and Jane did not continue with her career as a nurse after being diagnosed with diabetes during her training. Having diabetes made elements of their life risky, and choices were made as whether those risks were taken or not.

Royer (1998 p. 125) describes '*pacing*' – this is the balancing of daily activities with medical regimens, and examples of this have been observed in this study. Judith managed a busy work and home life, and adjusted her insulin according to her schedule, which at times differed to that prescribed by health care professionals. Royer also identifies a cognitive component to normalising and examples of this type of strategy were also observed. These included playing down the consequences of actions in relation to long term conditions as described by Irene, and optimising one's own situation by verbalising that things could be worse as in the case of Jane stating that things were

much better now than in the past. Refusing to be a victim as in the case of Tanya was also a manifestation of a cognitive strategy, as is acknowledging one's own personal characteristics, as in the case of Lynn who referred in a positive way to her sense of humour.

Although they were in the minority there were some women for whom living with diabetes was proving burdensome. Josie said in relation to her diabetes that *'I don't like it, I don't want it and there's nothing I can do about it'* (Interview data Josie 11). This is consistent with the *'worriers and agonizers'* group identified by Kelleher (1988, p. 150), half of a sample of thirty research participants, who adopted a passive role in relation to their diabetes. Joan had given up a career in senior management and spent most of her time in a darkened room and suffered many distressing physical symptoms which she attributed to the long term conditions of diabetes. This is also consistent with what Polonsky (1999) refers to as *'diabetes burnout'* and *'diabetes overwhelmedness'* in relation to diabetes related distress in daily life. This is when the demands of living with diabetes become too difficult to manage and extreme distress results.

8.1.4 Diabetes during times of crisis

In relation to this major theme discussed in Chapter 6, data collection was dependent upon retrospective recall of experience, as none of the women were experiencing times of crisis when interviewed. Times of crisis equated to the life events measured on the Social Readjustment Rating Scale (Holmes and Rahe, 1967) and also to the life events described by Brown and Harris (1989) in the Life Events and Difficulties scale. Holmes and Rahe described life events as those events requiring readjustment and which are significantly associated with psychological disturbance and exacerbation of illness. Lloyd et al. (1999), using the Life Events and Difficulties Schedule of Brown and Harris, found that severe personal stressors were associated with poor glycaemic control, whereas positive events were associated with fair or improved control. Women were significantly more likely to maintain poor glycaemic control over time than men, being more likely to report severe

personal stressors. Lloyd et al. (1999) refer to different classifications of stressor – life events, long term difficulties, severe personal stressor events and positive events. The first three of these are events which could occur during times of crisis as described by women in this study such as caring for a dying child in the case of Annette, or dealing with the redundancy of a spouse as in the case of Lois. The majority of these events were concerned with meeting the needs of others rather than their own needs, the latter adopting a secondary position including the care of their own diabetes. An exception to this was Paula who left the side of her dying father to attend to her own needs in relation to her diabetes, which she reported as being due to the fact that she did not want her mother to be concerned about her. One alternative explanation could be that she was utilising her diabetes as an excuse to remove herself from a stressful situation. Many of the crisis events described also related to the multiple roles with which the women engaged such as childcare, care of elderly parents, work related roles and family commitments. Other crisis events described by the women related to their own needs, and were psychological or physical in nature, some relating to diabetes such as hypoglycaemia and others to other health events such as breast cancer. There was no pattern as to whether the women perceived that their diabetes was affected by such events – for some women there was a reported marked increase in blood glucose levels, and for others there appeared to be no effect. Explanations for this could be that it was not experience of the event alone that was responsible for the effect on blood glucose levels. Mediating factors could include the personality of the individual themselves as asserted by Selye (1956, p. vii) when he stated '*the same stress which makes one person sick can be an invigorating experience for another*'. The social context within which an event occurred could also influence this health status, particularly in relation to the social support received (Berkman, 2000). Relationships may act to protect against or reduce the effects of stress, as described in Brown and Harris's work on stress and depression (Brown and Harris, 1978; Cohen and Syme, 1985), where social support is referred to as a buffer to stress and the onset of depression. Stress in itself may not lead to depression;

the presence of other vulnerability factors may be required such as having young children or the absence of social support. Gina's description of experiencing several events concurrently, within a scenario of losing two major sources of support by her husband and mother, lends credence to this view. Conversely however, some relationships identified within this thesis were more of a stressor than a buffer, as in the case of Marge's husband wishing to be inappropriately involved with her diabetes care and Judith's troubled relationship with her adolescent daughter.

This research has shown that the experience of stress is related to the situation within which women find themselves. Previously discussed explanations for the differing experiences of women relate to the social context and circumstances of the woman at the time that the stress occurred and the support mechanisms that may be in place. Prior experience of dealing with stressors in relation to diabetes may also play a part in how resilient women are in dealing with the situation at the time, and may affect how well the diabetes is controlled, particularly if the stress relates to diabetes itself, as in the case of ketoacidosis as described by both Judith and Gina.

Examination of the themes of managing diabetes in daily life and at times of crisis links to the key theoretical concepts of feminist research and empowerment underpinning this thesis by highlighting knowledge of the psychosocial, as well as the medical, aspects of living with diabetes for this group of women with diabetes . This previously subjugated knowledge was previously unavailable to those planning and delivering diabetes care, and there is now the potential for this to be integrated into future models of care. This is discussed further in Chapter 9.

8.1.5 A spiralling effect

The cyclical process of living with stress and diabetes can be conceptualised as having the potential to become a spiralling one (Figure 8.1).

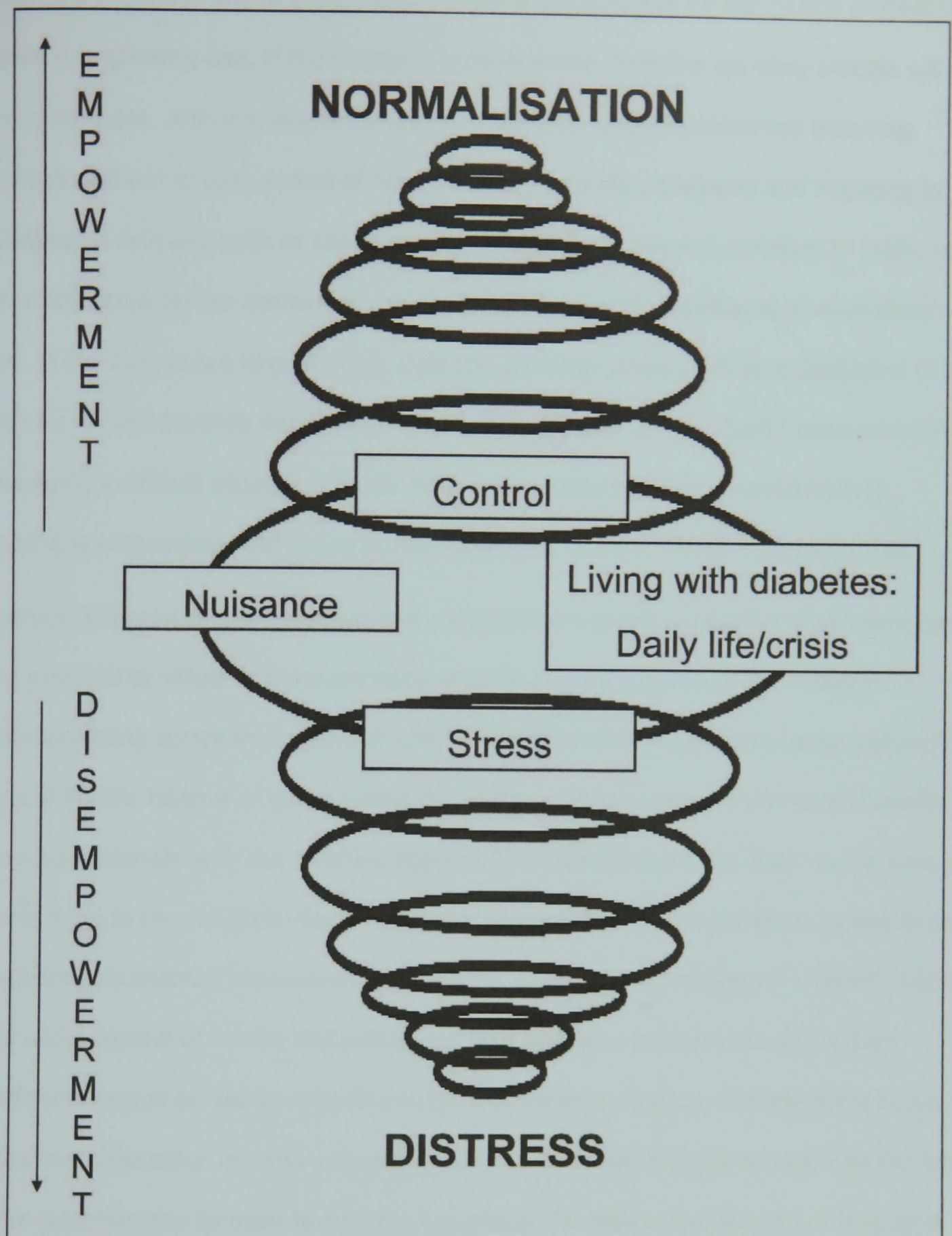


Figure 8.1 Diagrammatic representation of the spiralling relationship between stress and diabetes

The overall findings of this research can be represented in diagrammatic form, as shown here in Figure 8.1. It can be seen from this figure that the process of living with diabetes in the context of daily life and at times of crisis involves women dealing with stress and nuisance in an attempt to control diabetes in the social context within which they live. This is a cyclical process providing that these components remain constant. However, if

there is a change in any of these factors, there is the potential for the cyclical process to become a spiralling one. If the change is a positive one, then the spiralling process will be an upward one, with movement towards normalisation and empowerment occurring.

Tanya's decision to take control of her diabetes shortly after diagnosis and engaging in challenging activities such as sailing across the Atlantic Ocean and travelling to India, both of which increased her confidence and ability to manage her diabetes is an example of this. If the change is a negative one, then the spiralling process will be a downward one with movement towards distress and disempowerment occurring. Claire's experience of managing a difficult situation with her mother and suffering severe hypoglycaemia, becoming unconscious and subsequently feeling out of control is an example of this.

Applying the principles of feminism and empowerment to this conceptual framework has the potential to influence the experience of women living with stress and diabetes. A disempowering compliance approach can be transformed into an empowering approach by shifting the balance of power within the relationship between the women and health care professionals, with the resulting impact on the spiralling process itself due to women being more in control within the consultation process. This can be achieved by health care professionals enabling the woman to define the agenda for managing her diabetes within the social context of her life and setting her own agenda. However, this will require additional resources, particularly time in the initial stages, and may therefore not be an attractive proposition in today's economic climate. This may be false economy as the long term outcome may be more favourable in terms of the lesser development of long term complications of diabetes, both physical and emotional. A future longitudinal study would be appropriate to investigate this. Empowerment as it is defined within the NSF (DOH, 2001) pays only lip service to the concept, as it is embedded within the current system for the provision of health care. In order to succeed, more resources need to be made available for implementation of an empowerment model of care such as that described by Anderson and Funnell (2010) , together with education programmes aimed at members of all health care professions, at both undergraduate and postgraduate level. Similar

programmes could be made available to women with diabetes with an emphasis on the development of assertiveness skills to enable challenges to be made to health care professionals where appropriate, with the aim of achieving mutual respect and understanding. The generic Expert Patient Programme (DOH, 2004) is a step in the right direction towards these goals, and the principles could be applied to specific gender – related programmes in diabetes care.

The gap between a woman who has achieved the state of normalisation and that of a woman in distress can be compared to diabetes being a '*bit of a nuisance*' and '*a bloody nuisance*' identified within the poetic representation of the continuum of diabetes experience. Vulnerability of the women, and perception of the nuisance factor of diabetes, is likely to be greater during times of crisis than in everyday life, as control of a situation (and diabetes) is much more difficult to maintain in a crisis whereas there is usually an element of planning in everyday life. A similar comparison may be made between a woman who is stressed and one who is in control of her life and diabetes. It is not only the emotional effect of her stress or distress that would be apparent, but also the effect upon the diabetes itself and the likely loss of glycaemic control, both in the short and long term health outcomes, which is detrimental to both the women in individual terms and the wider health care agenda.

There is always the potential for the spiralling process to change direction due to the unpredictability of the interaction between stressful experiences and diabetes. The implications for practice of the recognition of the spiralling effect and the contribution of this research to the existing literature will be discussed in the concluding chapter of this thesis.

8.2 The research process

8.2.1 Research methodology and methods

As shown in Chapter 2, an extensive literature review has not identified any other qualitative research examining diabetes related stress in women in midlife. The pragmatic approach to sequential exploratory mixed methods methodology within a feminist empowerment framework in this thesis has been driven by the research questions asked, and the broader theoretical assumptions of phenomenology underpinning them. An assumption was made of a relationship between experience, language and meaning, with meaning and experience being reflected in the language used. A focus group was employed as a methodological technique for informing the study design and identified areas for further exploration and informed the development of the *Living with Diabetes Questionnaire (LWDQ)*. This questionnaire was utilised to identify the extent to which stress was an issue for women living with diabetes, and to describe the characteristics and identify the sample of women who were included in the main stage of the study. This final stage of the sequential data collection was given the highest priority due to the nature of the research questions relating to the understanding of the experience of living with diabetes. The analysis process and presentation of results involved a creative and active role (Sparkes, 2002), rather than a passive one, on my part as the researcher. The aim of IPA analysis, which is data driven and inductive in its approach, was to provide a rich description of themes analysed from the data as shown in Figure 3.2.

Using such a '*bricolage*' (Section 3.5) of methods enabled examination of the women's experiences of the complexity of living with a long term condition in midlife, in both biomedical and psychosocial terms, at a deeper level. The research environment may have impacted upon the findings, as all data collection (with the exception of Josie who was interviewed in the workplace) took place in the women's home, rather than a clinical environment. A high response rate was achieved in the survey stage (88%), interviews

(100%) and journal keeping (72%). This suggests a perceived need to discuss issues which are not normally talked about, and which was confirmed in the qualitative data in both interview and LWDQ responses.

Empowerment within the research process was an important issue as the aim of the research in feminist terms was to hear the voices of the women, who were in a position of relative powerlessness in terms of a medical hierarchy of knowledge. The relationship between me and the research participants could be likened to that between health care professionals and the women with diabetes because as a researcher I may have been perceived as being in a position of power. However, I viewed the interviews as '*meetings between experts*' (Tuckett et al., 1985). At an individual level I was striving for the relationship of '*mutual participation*' (Szasz and Hollender, 1956) where contributions from both myself and the women were recognized. In the context of this research face to face interaction took place within an interview setting, usually within the women's homes. This placed the research participant and me within a specific relationship. A negotiation of power relationships occurred, with the women and I initially being in a '*stranger-stranger*' relationship, and moving on in a '*guest – host*' manner (Cartwright and Limandri, 1997 p.223). I am hesitant to use the term '*friend*' as this would suggest an ongoing relationship, and interactions took place (usually) on a single occasion only. I was more a '*friendly stranger*' (Finch, 1993, p. 74) or '*friendly guest*' (Reinharz, 1992, p. 27). To some extent I was the representation of Lorber's (1997) '*voice of medicine*' and the women represented the '*voice of the lifeworld*'.

Voices are little heard in clinical practice often due to the constraints of the environment and time. However, in contrast to the voice of medicine prevailing, my aim in feminist terms was to give priority to the voices of the women being interviewed, and to make these personal and private constructions public. By dressing in a non powerful manner, I tried to avoid appearing dominant in the interactions. An atmosphere of mutual trust was established – I trusted that the women were telling me an account which reflected their experience and that I was safe within their houses. The women trusted

that I would not misrepresent their stories, ensuring consistency between what I said and what I did. A mutual competence was acknowledged – the women were competent at dealing with their lives with diabetes, and I was competent (under supervision) within the research process. A non judgemental stance was adopted in that there was no expectation of success or failure, and I accepted their experiences described without comment. Several women commented that the interview was the first opportunity they had had to talk about their lives with diabetes in this way, and also indicated that this was in direct opposition to their experiences with some health care professionals.

8.2.2 Reflexivity within the research process

Although the fieldwork for this thesis took place within a time frame of approximately fifteen months, reflexivity has been a feature of the research process from conception of the research topic to dissemination of results. My role within this thesis is to make the previously private accounts of the women public, to academic, professional and lay audiences. Reflexivity is closely allied to self reflection, but goes beyond this. Finlay's (2005, p. 532) definition is used in the context of this thesis:

Reflexive analysis in research encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself. It involves a shift in our understanding of data collection from something objective that is accompanied through detached scrutiny of "what I know and how I know it", to recognising how we actively construct our knowledge.

Reflexivity entails acknowledgement of the role and influence of the researcher upon the project as a whole. This is underpinned by the underlying methodological position which defined the course of the study, whilst allowing the research questions to direct the data collection methods so that the topic under investigation could be best studied. The context of the philosophical values affected the methodology and the interpretation of the research findings. It is therefore important to acknowledge my ideological viewpoint

taken, as this will contribute to the understanding of the phenomenon being studied. This thesis is supported by a feminist viewpoint, in which the women-centeredness of the research is acknowledged. Women's experiences and accounts are valued, with face to face interaction being as important as written communications, within an atmosphere of mutual trust.

In feminist terms, although it could be argued that I was more powerful in terms of determining the design and implementation of the research process, I attempted to redistribute the power, by following the women's lead in the structure of the interview, where appropriate. A key principle for me was that of reciprocity – giving something back in exchange. Questions were answered if asked, and reassurance given – several women asked for this in relation to whether they were the only person identifying specific problems. My feelings were that I had a moral duty to answer questions and anxieties as honestly as possible. This was in line with Anderson (1991) and Oakley's (1981) views as discussed in Section 3.4.5. This practice is endorsed by Reinharz (1992, p. 27) as '*good feminist practice*'. For some women, the interview was the only chance that they had had to discuss their diabetes in such an in-depth manner, in an environment which they perceived to be non-judgemental, and within which a mutual warmth and respect developed. An opportunity was also provided to make sense of their experience and to learn more about the research process and further areas for discussion were opened up.

As well as a having personal interest, I came to this research as a mature woman in midlife, sharing some features of the women in the study, namely multiple roles, gender and age. What I did not share was the experience of living with diabetes. However, at times, my experience as a researcher mirrored that of the research participants, in that the research became something to be managed in the context of an already busy life, in which I had multiple roles. I was expected to comply with predetermined boundaries, and interacted with individuals who I perceived to be in positions of power, and at times felt disempowered. Significantly, during the period of writing up of the thesis I was diagnosed with a long term cardiac condition, which

required me to make changes to my lifestyle, adhere to a medication regimen and reassess psychosocial aspects of life, which mirrored many of the women's reported experiences.

My interest in studying stress and diabetes as a phenomenon came from my previous clinical experience as clinical nurse specialist in diabetes, and it was this previous role which will be discussed in relation to personal tensions in role and identity. In Johnson and Macleod Clarke's study of the impact on researchers of collecting sensitive data, they noted that issues relating to role conflict emanated mainly from qualified nurses (Johnson and Macleod Clarke, 2003). Professional socialisation had led to the conditioning of my behaviour to behave in certain ways and within professional boundaries. There was an innate concern not to inflict any harm on the women interviewed. Having made a commitment to maintain confidentiality at all times, and not to contact any health care professional involved with their care, this meant that I could not pass on any information even when there was the potential for harm to ensue, such as when references were made to suicide and or to actions which hugely deviated from prescribed treatment regimes. However all women had volunteered, rather than been approached, to take part in the study.

However, in the context of this study, the notion of critical reflexivity refers not only to rigour, but to the acknowledgement of the nature and function of power within the research process (McCabe and Holmes, 2009), which can be used to achieve the goals of empowerment and emancipation central to feminist research.

It could be argued that taking part in such research had a therapeutic aspect for the research participants. However, Swanson (1986) argued that researchers are not usually therapists and should refer to appropriate professionals where necessary. My view is that researchers from caring professions are likely to possess some skills, and have the professional knowledge to know when referral is necessary. What may be less easy for researchers to deal with is the stress that they themselves may feel, leading to feelings of

isolation and a need for supervision and guidance. Rager (2005) suggests that peer debriefing within a supportive group environment and journal writing may be helpful, strategies which I found useful following some interviews.

Two potentially stressful incidents for both the women and myself related to two hypoglycaemic attacks which were observed during the course of the interviews. The women affected were Carol and Annette, the first and last women to be interviewed. Carol's interview was the longest, lasting almost five hours. She began to talk as soon as I entered the house, and continued for 45 minutes, before I spoke. It was a morning interview and she mentioned that she had been gardening as I arrived. Approximately half way through the interview, Carol herself identified that she was feeling hypoglycaemic, demonstrating that she was having warning signs:

Do you know something? I think I'm beginning to go hypo at the moment, so if I can just go and get some fruit juice.

(Interview data Carol 1070–1073)

At no time leading up to the above comment was I aware that Carol was demonstrating any signs of hypoglycaemia. She did not appear to have any cognitive impairment, or be distressed in any way, and maintained control of the situation herself throughout. The interview was barely disrupted, as we stopped for lunch at that point, and resumed again within half an hour. Although we were alone in the house, at no point did I feel that I needed to intervene in a professional role, something about which she commented in a positive way. I was also aware that we were close to medical facilities should her condition worsen to any great extent.

The observation of Annette's hypo was in stark contrast to this. She lived in a remote part of the British Isles, and her interview took place during the late morning. Her husband and two children were at home. The interview started well, but after about half an hour, Annette's speech was becoming progressively slower, and some of her answers, although relevant to diabetes, did not appear to answer the questions asked, and her

narrative was interspersed with long pauses. At this point I was aware that Annette may be hypoglycaemic, and I felt a sense of responsibility towards her both as a researcher and a practitioner. As a researcher it appeared to be inappropriate to use data, when her cognitive processes were impaired, and I felt a moral responsibility to stop the interview. However, the dilemma for me as a practitioner was that this would mean that I was taking control of the situation, and Annette had made it clear that being in control was important to her. I was also aware that we were many miles from emergency medical facilities should they be required. The other consideration was that it may not have been that she was hypoglycaemic, and this was her normal pattern of communication, I had only met her for the first time that day. I had made the decision to intervene and suggest she measured her blood glucose levels in order to take action to enable her to take control, when she stated that she thought she should do so, although her speech was somewhat disjointed, and I felt did require prompting.

Annette (sighs) I don't think (LONG PAUSE) well, right now for instance, if I were to do a blood test, um, I actually do think that right now I need to do a blood test, for instance, and in that respect, yes.

Julie OK

Annette Yes, it affects my life.

Julie Do you want to do a blood test now?

Annette Yes.

(Interview data Annette526–541)

Her blood glucose level was 1.9 mmols per litre, indicating that she was severely hypoglycaemic. At that point her husband came into the room, recognised that she was hypoglycaemic and gave her glucose tablets, and made her lunch, and I was able to observe at first hand her dependence upon him. It became clear during lunch that her teenage children also felt a degree of responsibility towards her. They had been

frightened by a previous event, when Annette had been fine when they left for school in the morning, but when they returned at lunchtime they found her hypoglycaemic in a bath full of cold water, with potentially fatal consequences. Her son wanted to stay off school to look after her, and her daughter often rang her mother to check that she was OK, and her husband commented that he perceived himself to be her carer. Although her hypoglycaemia had been treated, I was unsure as to whether she was fully functioning for the remainder of the interview. My dilemma as a researcher was that due to transport arrangements I had to leave to catch a long distance train. We arranged that I would ring her the following day to make a decision how to proceed. During this conversation she stated that she only had memory of her responses up to the section on roles, and had no memory of the continuation of the interview after lunch. We agreed that questions after the section on roles would be repeated and data from the interview following those sections would be destroyed, and a mutually agreeable time to continue the interview was arranged for the following week. Her main concern was that she had disrupted the interview process and that she may have behaved in a way that was embarrassing to her, and she was reassured on both counts.

Both women experienced hypoglycaemia in a context that would normally have been private, in their own home. By being observed having a hypo, this made their experience public, and their identity in relation to diabetes became prominent. Up to that point, although women were *recounting* their experiences of diabetes, they were doing so in a *normalising* role and context. Neither woman took on the persona of '*worriers and agonizers*' (Kelleher, 1988 p.150) and diabetes did not appear to dominate their daily life. Both described days that included a variety of social roles which involved relationships with different groups of people and both reported that they considered themselves as being in control of their diabetes. However, it could be argued that they were in fact '*adapting*' (Kelleher, 1988) to their diabetes, by accepting a revised way of living. In terms of empowerment, Carol managed the situation herself and successfully treated the hypo.

However, Annette required help from her husband, and at that point could be considered disempowered in relation to her health and took on a '*sick role*' (Parsons, 1975).

My reflections on this reflexive section are that it made little difference to this research study whether I was acting as a researcher or a nurse, as I had invested aspects of the self within each role and employed the same principles in relation to empowerment and respect for others within each role (Anderson, 1996; Paterson, 2001). If the research had taken place within a clinical environment, there could potentially have been a perceived difference in the power relationship between myself and the research participants. However, regardless of the environment in which I was in, and whether I was functioning as a nurse or a researcher I was bound by the professional code of conduct relevant to all practising registered nurses within the UK, which requires the taking of appropriate action to deal with a situation that is potentially damaging to an individual and to provide a safe environment.

8.2.3 Rigour within the research process

Criteria for measuring the rigour of this research (Hall and Stevens, 1991) were identified in Section 3.5.4. A reflection on whether or not each has been achieved is given below.

- Dependability – the data has remained in context as far as possible, although some decontextualization is inevitable when using quotes within the text of the thesis. Although repeatability is not required, identification of common themes across respondents was apparent. Methodological and analytical decision making trails are illustrated in the diagrams within the results chapters of this thesis.
- Adequacy – the research process and outcomes are relevant to the research questions asked in terms of accessing previously subjugated knowledge held by a group of women in relation to their experience of living with stress and diabetes.

- Critical reflexivity – the participation of my role as the researcher has been made explicit throughout the thesis, and the principles of feminism and empowerment are illustrated in Section 8.2.1 and 8.2.2.
- Credibility – a preliminary narrative account of collective experience written in the first person was returned to all the women interviewed, and their comments invited. Five women responded and all could recognize elements of their experiences within the account. The response to the poetic representation by people external to the group of women interviewed has been discussed in Section 8.1.2.
- Rapport – an atmosphere of trust and openness was facilitated throughout the research process both by myself as the researcher and the women participants.
- Coherence – the research findings are consistent and contextualised within the women's lives.
- Complexity – the complexity of the women's lives are reflected within the research findings, and are located in the context of their lives and also a larger medico–social-political context, as described below.
- Consensus – recurring themes have been identified within the data, using different data sources within the methodological framework of pragmatic mixed methods research.
- Relevance of findings – in feminist terms, the issues raised by the women have been addressed and the findings have the potential to improve women's lives as discussed below.
- Honesty and mutuality are linked to the concepts of rapport discussed above, and were implicit in the ethical principles underpinning this study.

- Naming – women's own terms were used to define themes and the poetic representation of results, and were also used in quotations throughout the thesis.
- Relationality – a collaborative stance was taken in relation to the development of the research process and data collection. Endeavours were made as far as possible for the process to be non – hierarchical, but as there are no claims for this research to be within a participatory framework, a degree of power imbalance was inevitable.

This research has challenged the accepted version of the experience of women living with diabetes, by changing the focus of what Foucault terms (1973) the '*clinical gaze*'. The focus has shifted away from the traditional medical model of care imposed by the medical profession to a psychosocial empowerment approach determined by the women themselves. This has allowed access to experiential knowledge that was previously subjugated in favour of medical knowledge, and in feminist terms this thesis has been facilitative in making this knowledge public, with a view to disseminating it to both professional and lay audiences to make it a part of the mainstream knowledge of diabetes, and integrated into the existing and future health care system.

The findings from this research have implications for theory and its application to practice and these are discussed in the following conclusion.

CHAPTER 9

Drawing to a close – Conclusion

By giving voice to the women as service-users a new dimension of knowledge and awareness has been added to the existing body of medical knowledge in diabetes. Intertwining the women's experiential and tacit knowledge with the received knowledge of health care professionals provides an additional perspective to the existing literature. This thesis offers an original contribution to the field through the identification of diabetes as a nuisance, and illuminating the complexity of managing life with diabetes by women in midlife. This thesis argues that women in midlife who live with diabetes experience stress to a greater or lesser degree. Experience of stress was not uniform, and the perceptions of the women showed considerable variation according to the type of stress and the social context of their lives at that particular time. A more in-depth understanding of the cyclical and often spiralling relationship between a whole range of stressors, in both daily life and at times of crisis, has been achieved as a result of this study. Issues of stress and control have been considered in relation to the major themes of *diabetes as a nuisance*, *diabetes in daily life* and *diabetes at times of crisis*. Reports of experience have been accessed at a deeper level than that which occurs during medical consultations, or through surveys or other quantitative methods of data collection, allowing for analysis of areas not normally discussed. There is no intent to minimise the importance of medical knowledge regarding glycaemic control, but rather to complement it with experiential knowledge. In this way, a more holistic picture of the experience of living with diabetes is gained, to allow for knowledge transfer into practice. Traditional models of medical consultation and care do not lend themselves to facilitating discussion of the in-depth

experience of living with diabetes and formulating goals for care that are shared between the health care professional and the person with diabetes (Ainsworth-Vaughn, 1998). This is due to the unequal balance of power and knowledge. It is therefore suggested that a move away from the compliance model (Trostle, 1988) and towards an empowerment model (Anderson, 1996; Anderson and Funnell, 2010) is a more appropriate approach to diabetes care, leading to a greater potential for mutual understanding and respect between patient and practitioner, as identified in recent government policy (DOH, 2001). Integration of a spiralling model of managing diabetes would allow for identification of the potential for a change in the direction of the spiral and early intervention to occur.

By contributing a previously unheard voice to the body of knowledge relating to the experience of living with diabetes, this research has the potential to influence future care of women living with diabetes. Findings from this qualitative research could inform the development of a more person-focused approach to patient consultation, within an empowerment framework (DOH, 2001, 2010). This has the potential to be combined with previous approaches to empowerment in diabetes care (Anderson et al., 1991) to develop a model of care specific to women with diabetes. Clinical applications may be made by integrating the findings from this study into clinical interventions such as education sessions, and also by implementation of the principles of empowerment into clinical consultations with a shared focus between psychosocial and biomedical aspects of care. Although the care of the women who took part in this study may not be affected, findings of the study may inform the ways in which health care professionals can improve their work with women with diabetes. By integrating the knowledge of the experience of women living with diabetes into an empowerment model of care, and incorporating the notion of diabetes as a nuisance and the experience of stress in daily life and at times of crisis into a treatment model for diabetes, the boundaries of diabetes care will be extended to include psycho social as well as medical principles. The spiralling conceptual framework could be utilized as an assessment tool for women to self assess the degree of control or stress they are experiencing in their everyday lives and at times of crisis in

relation to their diabetes care. However, further research is required in order to examine the utility of such an approach. There is the potential for this to be incorporated into a feminist participatory action research project

Involving women with the experience of living with diabetes in educational programmes will add legitimacy to this experiential knowledge base. This knowledge also has the potential to be integrated into government health policy, facilitated by health care professionals acting as advocates if necessary. Indeed service user involvement in both research and practice is becoming and is recommended by bodies such as the NHS Institute for Innovation and Improvement.

The findings of the research will be disseminated to both lay and professional audiences, again with the aim of producing a shared knowledge base. Articles will be submitted to peer-reviewed journals and presented at local, national and international conferences. Submissions will also be made to popular media such as magazines and radio programmes, and also through the service-user organization Diabetes UK and their Balance magazine. An application will be made to Woman's Hour broadcast on BBC Radio 4 to disseminate the findings to as large an audience of women (and men) as possible. The use of a mixed methods approach has resulted in data of different types, the representation of which will appeal to a variety of audiences. However, the underlying message and aims of raising the profile of the women's experiential knowledge will be the same.

There is no intention to generalise from the results of this study and this is recognized as a limitation to the research, in that the findings are only applicable to this group of women. However, when the results have been discussed in a variety of forums, women have commented that they recognized elements of the findings. The sample consisted of a small self-selected group of women who were purposively sampled and were of homogenous age and ethnicity. Co-constructions occurred within a specific

context, time and place. However, this is not to say that the research process was less than rigorous.

Given that there is little specific research in this area, it follows that there is the potential for future research in this area. It is now nearly ten years since the original data was collected and there is the potential for a follow-up study with the same group of women, particularly in relation to the development of long term complications and the effect of these on their lives. It is also likely that social roles may have changed, particularly in relation to work, as many of the women will now be of retirement age. There is potential for future longitudinal research which examines more closely the links between psychological stress and control, which could include assessment of personality and mental health. Gendered comparative studies could be undertaken in relation to roles and relationships.

In conclusion, this thesis has addressed the research questions identified in Chapter One relating to women's experiences of stress in relation to living with diabetes. Stressful experiences, their impact and interpretation, and the meanings women gave to their lives have been considered in the light of the concepts of stress and control. Diabetes, both during daily life and at times of crisis, has been positioned as a nuisance in a psychosocial rather than a medical context. Living with diabetes is a dynamic changing process, with constant interaction between the medical and psychosocial components of management. As Lynn said:

It's like a circle, and it goes round. It's a case of what goes round comes round, so one has got to affect the other and then the other goes back round to affect it.

(Interview data Lynn 1599–1601)

BIBLIOGRAPHY

- Agrawal, A. and Pandey, A. (1998) 'Coping with chronic disease; role of psychosocial variables', *Psychological Studies*, 43, pp. 58–64.
- Aikens, J.E., Wallander, J.L., Bell, D.S. and McNorton, A. (1994) 'A nomothetic-idiographic study of daily psychological stress and blood glucose in women with type I diabetes mellitus', *J Behav Med*, 17, pp. 535–48.
- Aikens, J.E., Wallander, J.L., Bell, D.S. and Cole, J.A. (1992) 'Daily stress variability, learned resourcefulness, regimen adherence, and metabolic control in type I diabetes mellitus: evaluation of a path model', *J Consult Clin Psychol*, 60, pp. 113–8.
- Ainsworth-Vaughn, N. (1998) *Claiming Power in Doctor-Patient Talk*, New York, Oxford University Press.
- Alonzo, A.A. (2000) 'The experience of chronic illness and post-traumatic stress disorder: the consequences of cumulative adversity', *Social Science and Medicine*, 50, pp. 1475–1484.
- Anderson, J. (1991) 'Reflexivity in fieldwork: towards a feminist epistemology', *Image Journal of nursing Scholarship*, 23, pp. 115–118.
- Anderson, J.M. (1996) 'Empowering patients: issues and strategies', *Soc. Sci. Med*, 43, pp. 697–705.
- Anderson, J.M., Wiggins, S., Rajwani, R., Holbrook, A., Blue, C. and Ng, M. (1995) 'Living with a chronic illness: Chinese Canadian and Euro-Canadian women with diabetes-exploring factors that influence management', *Social Science and Medicine*, 41, pp. 181–195.

- Anderson, R. (2001) 'Qualitative research in diabetes: the role of stories in the culture of science', *The Diabetes Educator*, 27, pp. 798–808.
- Anderson, R. (1995b) 'Patient empowerment and the traditional medical model: a case of irreconcilable differences?', *Diabetes Care*, 18, pp. 412–415.
- Anderson, R. and Bury, M. (eds) (1988) *Living with Chronic Disease: The experience of patients and their families*, London, Unwin Hyman.
- Anderson, R. and Funnell, M. (2010) 'Patient empowerment', *Patient Education and Counselling*, 79, pp. 277–282.
- Anderson, R., Funnell, M., Barr, P. and Al, E. (1991) 'Learning to empower patients: results of professional education program for diabetes educators', *Diabetes Care*, 14, pp. 584–590.
- Anderson, R., Funnell, M., Butler, P., Arnold, M., Fitzgerald, J. and Feste, C. (1995a) 'Patient empowerment', *Diabetes Care*, 18, pp. 943–949.
- Anderson, R.M., Funnell, M.M., Fitzgerald, J.T. and Marrero, D.G. (2000) 'The diabetes empowerment scale – A measure of psychosocial self-efficacy', *Diabetes Care*, 23, pp. 739–743.
- Anderson, R. M., Goddard, C. E., Garcia, R., Guzman, J. R. and Vazquez, F. (1998) 'Using focus groups to identify diabetes care and education issues for Latinos with diabetes', *Diabetes Educ*, 24, pp. 618–25.
- APPG/Diabetes UK (2006) *Diabetes and the disadvantaged: reducing health inequalities in the UK World Diabetes Day 14 November 2006*, in APPG (ed.) London.
- Atkinson, M. and Eisenbarth, G. (2001) 'Type 1 diabetes: new perspectives on disease pathogenesis and treatment', *Lancet*, 358, pp. 221–229.
- Audit Commission (2000) *Testing times: a review of diabetes services in England and Wales*, London, Audit Commission.
- Aujolat, I., Luminet, O. and Deccache, A. (2007) 'The perspective of patients on their experience of powerlessness', *Qualitative Health Research*, 17, pp. 772–785.

- Baksi, A. and Cradock, S. (2001) *Empowerment of People with Diabetes*, The Isle of Wight Diabetes Centre.
- Barnard, K., Skinner, T. and Peveler, R. (2006) 'The prevalence of o-morbid depression in adults with Type 1 diabetes: systematic literature review', *Diabetic Medicine*, 23, pp. 445–448.
- Barnett, R. and Baruch, G. (1985) 'Women's involvement in multiple roles and psychological distress', *Journal of Personality and Social Psychology*, 49, pp. 135–145.
- Barrett, T. (2011) 'Breakthroughs in action research through poetry', *Educational Action Researcher*, 19, pp. 5–21.
- Beauchamp, T. and Childress, J. (1994) *Principles of Biomedical Ethics*, New York, Oxford University Press.
- Begum, S. and Por, J. (2010) 'The impact of the NSF for diabetes on patient empowerment', *British Journal of Nursing*, 19, pp. 887–890.
- Bell, L. (1998) 'Public and private meanings in diaries – Researching family and childcare', in Ribbens, J. and Edwards, R. (eds) *Feminist Dilemmas in Qualitative Research-Public Knowledge and Private Lives*. London, Sage.
- Berg, M. and Honkasalo, M. (2000) 'Pregnancy and diabetes – a hermeneutic phenomenological study', *Journal of Psychosomatic Obstetrics and Gynaecology*, 21, pp. 39–48.
- Berkman, L. (2000) 'Social support, social networks, social cohesion and health', *Social Work in Health Care*, 31, pp. 3–14.
- Biggerstaff, D. and Thompson, A. (2008) 'Interpretative Phenomenological Analysis (IPA): A qualitative methodology of choice in healthcare research', *Qualitative Research in Psychology*, 5, pp. 214–224.
- Biggs, M. (1993) 'Insulin withholding for weight control: An eating disorder in women with diabetes?', *Dissertation Abstracts International*, 54, 1883B.

- Birch, M. (2000) 'Inviting intimacy: the interview as therapeutic opportunity', *International Journal of Social Research Methodology*, 3, pp. 189–202.
- Bolton, G. (1998) 'Stories of Dying: therapeutic writing in hospice care', in Greenhalgh, T. and Hurwitz, B. (eds) *Narrative Based Medicine – dialogue and discourse in clinical practice*, London, BMJ Books.
- Bondi, L. and Buman, E. (2001) 'Women and mental health: A feminist review', *Feminist Review*, 68, pp. 6–33.
- Bowling, A. (1997) *Research Methods in Health*, Buckingham, Open University Press.
- Bradbury-Jones, C. (2007) 'Enhancing rigour in qualitative health research: Exploring subjectivity through the use of Peshkin's I's', *Journal of Advanced Nursing*, 59, pp. 290–298.
- Bradbury-Jones, C., Sambrook, S. and Irvine, F. (2008) 'Power and empowerment in nursing: a fourth theoretical approach', *Journal of Advanced Nursing*, 62, pp. 258–266.
- Bradley, C. (1979) 'Life events and the control of diabetes mellitus', *Journal of Psychosomatic Research*, 23, pp. 159–162.
- Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3, pp. 77–101.
- Brocki, J. and Weardon, A. (2006) 'A critical evaluation of the use of Interpretative Phenomenological Analysis (IPA) in health psychology', *Psychology and Health*, 21, pp. 87–108.
- Brody, H. (1998) 'Foreward', in Greenhalgh, T. and Hurwitz, B. (eds) *Narrative Based Medicine*, London, BMJ Books.
- Brown, G. and Harris, T. (eds.) (1989) *Life Events and Illness*, London, Unwin Hyman.
- Brown, G. and Harris, T. (1978) *Social Origins of Depression*, London, Tavistock.

- Brush, L. (1990) 'Violent acts and injurious outcomes in married couples: Methodological issues in the National Survey of Families and Households', *Gender and Society*, 4, pp. 56–67.
- Bryman, A. (1988) *Quality and Quantity in Social Research*, New York, NY, Unwin Hyman Ltd.
- Burgess, R. (1984) *In The Field – An introduction to field research*, London, Unwin Hyman.
- Burke Johnson, R. and Onuegbuzie, A. (2004) 'Mixed methods research: A research paradigm whose time has come', *Educational Researcher*, 33, pp. 14–26.
- Bury, M. (2001) 'Illness narratives: fact or fiction', *Sociology of Health and Illness*, 23, pp. 263–285.
- Bury, M. (1982) 'Chronic Illness as biographical disruption', *Sociology of Health and Medicine*, 4, pp. 167-182.
- Cartwright, J. and Limandri, B. (1997) 'The challenge of multiple roles in the qualitative clinician researcher – Participant client relationship', *Qualitative Health Research*, 2, pp. 223–235.
- Charmaz, K. (2001) 'Stories of suffering: Subjective tales and research narratives', *Qualitative Health Research*, 9, pp. 362–382.
- Chavasse, J.M. (1992) 'New dimensions of empowerment in nursing', *Journal of advanced Nursing*, 17, pp. 1–2.
- Cohen, S. and Syme, S. (eds) (1985) *Social Support and Health*, Pittsburgh, USA, Academic Press.
- Cohen, S., Kessler, C. and Underwood, G. (eds) (1995) *Measuring Stress: a guide for Health and Social Scientists*, New York, Oxford University Press.
- Confidential Enquiry into Maternal and Child Health (CEMACH) (2007) *Diabetes in pregnancy: Are we providing the best care?* London.

- Confidential Enquiry into Maternal and Child Health (CEMACH) (2005) *Pregnancy in women with Type 1 and Type 2 diabetes in 2002-03, England, Wales and Northern Ireland*, London.
- Connell, C. (1991) 'Psychosocial contexts of diabetes and older adults: reciprocal effects', *Diabetes Educator*, 17, pp. 364–371.
- Conrad, P. (2000) Qualitative Research on Chronic Illness: A Commentary on Method and Conceptual Development, *Social Science and Medicine*, 30, pp. –1263.
- Costacou, T. and Orchard, T.J. (2007) 'Menopause in women with type 1 diabetes', *Diabetes*, 56, A270.
- Coty, M. and Wallston, K. (2008) 'Roles and well-being among healthy women and women with rheumatoid arthritis', *Journal of Advanced Nursing*, 63, pp. 189–198.
- Coward, D. (1990) 'Critical multiplism: A research strategy for nursing science', *IMAGE: Journal of Nursing Scholarship*, 22, pp. 163–167.
- Cox, D. J., Taylor, A. G., Nowacek, G. and Al, E. (1984) 'The relationship between psychological stress and insulin-dependent diabetic blood glucose control: preliminary investigations', *Health Psychology*, 3, pp. 63–75.
- Creswell, J.W. (1998) *Qualitative Enquiry and Research Design – Choosing among five traditions*, Thousand Oaks, Sage.
- Creswell, J.W. and Plano Clark, V.L. (2007) *Designing and Conducting Mixed Methods Research*, London, Sage.
- Creswell, J.W., Shope, R., Plano Clark, V.L. and Green, D. (2006) 'How interpretive qualitative research extends mixed methods research', *Research in the Schools*, 13, pp. 1–11.
- Crotty, M. (1998) *The Foundations of Social research*, London, Sage.
- Crowther, C., Hiller, J. and Moss, J. (2005) 'Screening and active management reduced perinatal complications more than routine care in gestational diabetes', *Evidence-Based Medicine*, 10, p. 171.

- Cryer, P. (1996) *The Research Student's Guide to Success*, Buckingham, Open University Press.
- Daneman, D.E.A. (1998) 'Eating disorders in young women with Type 1 diabetes', *Hormone Research*, 50, p. 79.
- Danielson, K., Palta, M., Allen, C. and DJ, D.A. (2005) 'The association of increased total glycosylated hemoglobin levels with delayed age at menarche in young women with type 1 diabetes', *The Journal of Clinical Endocrinology and Metabolism*, 90, pp. 6466–6471.
- Davies, M., Heller, S., Skinner, T., Campbell, M., Carey, M., Cradock, S., Dallosso, H., Daly, H., Doherty, Y., Eaton, S., Fox, C., Oliver, L., Rantell, K., G.R. and Khunti, K. (2008) 'Effectiveness of The Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) Programme for people with newly diagnosed type 2 diabetes: cluster randomised controlled trial', *British Medical Journal*, 336, p. 491.
- de Witt, L. and Ploeg, J. (2006) 'Critical appraisal of rigor in interpretative phenomenological nursing research', *Journal of Advanced Nursing*, 55, pp. 215–229.
- Deem, R. (2002) 'Talking to Manager-Academics: Methodological dilemmas and feminist research strategies', *Sociology*, 36, pp. 835–855.
- Denzin, N.K. and Lincoln, Y.S. (eds) (2000) *Handbook of Qualitative Research*, Thousand Oaks, Sage.
- Denzin, N.K. and Lincoln, Y.S. (eds) (1998) *The Landscape of Qualitative Research – theories and issues*, Thousand Oaks, Sage.
- Department of Health (DOH) (2010) *Six years on: Delivering the Diabetes National Service Framework*, London, and Department of Health.
- Department of Health (DOH) (2005) *Supporting People with Long Term Conditions: An NHS and social care model to support local innovation and integration*, London, Department of Health.

- Department of Health (DOH) (2004) *The Expert Patient – A New Approach to Chronic Disease Management for the 21st Century*, London, Department of Health.
- Department of Health (DOH) (2001) *Diabetes National Service Framework for Diabetes Standards*, London, Department of Health.
- Diabetes Control and Complications Trial Research Group (DCCT) (1993) 'The effect of intensive treatment of diabetes on the development and progression of long-term complications in IDDM', *New England Journal of Medicine*, 329, pp. 977–986.
- Diabetes UK (2004) *Diabetes in the UK 2004*, London.
- Dominic, A. (1999) *Needles - a memoir*, London, Virago.
- Duffy, M.E. (1985) 'A critique of research: a feminist perspective', *Health care for women International*, 6, pp. 341–352.
- Elliott, H. (1997) 'The use of diaries in sociological research on health experience', *Sociological Research Online*, Vol. 2, No. 2.
- Enzlin, P., Mathieu, C., Vanderschueren, D. and Demyttenaere, K. (1998) 'Diabetes mellitus and female sexuality: a review of 25 years' research [see comments]', *Diabet Med*, 15, pp. 809–15.
- Erens, P., Primatesta, P. and Prior, G. (2001) *Health Survey for England: The health of minority ethnic groups*, in Health, D.O. (ed.) London.
- Fairburn, C.G., Peveler, R., Davies, B., Mann, J. and Mayou, R. (1991) 'Eating disorders in young women with insulin dependent diabetes mellitus: a controlled study', *British Medical Journal*, 303, pp. 17–20.
- Fekete, E. (2007) 'Gender and role influences on social control interactions and psychosocial well-being of couple living with type 2 diabetes', *Dissertation Abstracts International: Section B; The Sciences and Engineering*, 67, p. 6111.
- Feste, C. (1992) 'A practical look at patient empowerment', *Diabetes Care*, 15, pp. 922–925.

- Feste, C. and Anderson, R. (1995) 'Empowerment; from philosophy to practice', *Patient Education and Counselling*, 26, pp. 139–144.
- Finch, J. (1993) "'It's Great to have Someone to Talk to": Ethics and politics of Interviewing women', in Hammersley, M. (ed.) *Social Research-Philosophy, Politics and Practice*, London, Sage and the Open University.
- Finlay, L. (2005) "'Outing" the researcher: The provenance, process and practice of reflexivity', *Qualitative Health Research*, 12, pp. 531–545.
- Fitzgerald, J., Anderson, R. and Davis, W. (1995) 'Gender differences in diabetes attitudes and adherence', *Diabetes Educator*, 21, pp. 523–529.
- Fonow, M.M.A.C., J. (ed.) (1991) *Beyond Methodology: Feminist Scholarship as Lived Research*, Indiana, Indiana University Press.
- Foucault, M. (1973) *The Birth of the Clinic- an archeology of medical perception*, London, Tavistock.
- Franck, S.F.H. and Heukelbach, J. (2003) 'Tungiasis: more than an exotic nuisance', *Travel Medicine and Infectious Disease*, 57, pp. 159–66.
- Frank, A. (1995) *The Wounded Storyteller – Body, illness and ethics*, Chicago, The University of Chicago Press.
- Friedman, M. and Rosenman, R.H. (1959) 'Association of specific overt behaviour pattern with blood and cardiovascular findings', *Journal of the American Medical Association*, 169(12), pp. 1286–96.
- Friedman, S., Vila, G., Timsit, J., Boitard, C. and Mourensimeoni, M. (1998) 'Eating disorders and insulin-dependent diabetes mellitus (IDDM): relationships with glycaemic control and somatic complications', *Acta Psychiatrica Scandinavica*, 7, pp. 206–212.
- Funnell, M. and Anderson, R.E.A. (1991) 'Empowerment: an idea whose time has come in diabetic education', *The Diabetes Educator*, 17, pp. 37–41.
- Garner, P. (1995) 'Type 1 diabetes mellitus and pregnancy', *Lancet*, 346, pp. 157–161.

- Gatenby, B. (2000) 'Feminist participatory action research: Methodological and ethical issues', *Women's Studies International Forum*, 23, p. 89.
- Gibson, C.H. (1991) 'A concept analysis of empowerment'. *Journal of Advanced Nursing*, 16, pp. 354–361.
- Glaser, B. and Strauss, A. (1967) *The Discovery of Grounded Theory*, New York, Aldine de Gruyer.
- Glasgow, R. and Anderson, R. (1999) 'In diabetes care, moving from compliance to adherence is not enough', *Diabetes Care*, 22, pp. 2090–2091.
- Glesne, C. (1997) 'That rare feeling: Re-presenting research through poetic transcription', *Qualitative Inquiry*, 3, pp. 202–221.
- Godin, P. (2000) 'A dirty business: caring for people who are a nuisance or danger', *Journal of Advanced Nursing*, 32, pp. 1396–1402.
- Goetsch, V., Vandorsten, B., Pbert, L., Ullrich, I. and Yeater, R. (1993) 'Acute effects of laboratory stress on blood glucose in non insulin dependent diabetes', *Psychosomatic Medicine*, 55, pp. 492–496.
- Gonder-Frederick, L., Carter, W., Cox, D. and Clarke, W. (1990) 'Environmental stress and blood glucose change in insulin-dependent diabetes mellitus', *Health Psychology*, 9, pp. 503–515.
- Gonzalez, J., Safren, S., Delahanty, L., Cagliero, E., Wexler, D. and Meigs, J. (2008) 'Symptoms of depression prospectively predict poorer self-care in patients with Type 2 diabetes', *Diabetic Medicine*, 25, pp. 1102–1107.
- Grant, A.J. (1991) 'Body dissatisfaction in women with insulin-dependent diabetes mellitus', *Dissertation Abstracts International*, 53, 2543B.
- Greenhalgh, T. and Hurwitz, B. (eds) (1998) *Narrative Based Medicine*, London, BMJ Books.

- Griffin, C. and Phoenix, A. (1994) 'The relationship between qualitative and quantitative research: Lessons from feminist psychology', *Journal of Community and Applied Social Psychology*, 4, pp. 287–298.
- Gubrium, J. and Holstein, J. (1997) *The New Language of Qualitative Methodology*, Oxford, Oxford University Press.
- Hall, J. and Stevens, P. (1991) 'Rigor in feminist research', *Advances in Nursing Science*, 13, pp. 16–29.
- Hamilton, J. (1993) 'Feminist theory and health psychology: tools for an egalitarian, woman-centred approach to women's health', *Journal of Women's Health*, 2, pp. 49–54.
- Harding, S. (ed.) (1987) *Feminism and Methodology*, Indiana/Milton Keynes, Indiana University Press/Open University Press.
- Harding, S. (1991) *Whose Science? Whose Knowledge - Thinking from women's lives*, Milton Keynes, Open University Press.
- Harrison, K. and Barlow, J. (1995) 'Focused Group Discussion: A "quality" method for health research?', *Health Psychology Update*, 20, pp. 11–13.
- Hartsock, N. (1987) 'The feminist standpoint', in Harding, S. (ed.) *Feminism and Methodology*. Bloomington/Milton Keynes, Indiana University Press/The Open University Press.
- Hepworth, J. (1999) 'Gender and the capacity of women with NIDDM to implement medical advice', *Scand J Public Health*, 27, pp. 260–6.
- Hicks, D. (2010) 'NSF for diabetes: How are we doing?', *Journal of Diabetes Nursing*, 14, p. 126.
- Hinkle, L.E. (1974) 'The concept of "stress" in the biological and social sciences', *International Journal of Psychiatric Medicine*, 5, pp. 355–357.

- Hinkle, L.E. and Wolf, S. (1952) 'The effects of stressful life situations on the concentration of blood glucose in diabetic and non-diabetic humans', *Diabetes*, 1, pp. 383–392.
- Holmes, T.H. and Rahe, R.H. (1967) 'The social readjustment rating scale', *Journal of Psychosomatic Research*, 4, pp. 213–218.
- Holt, R. (2008) 'Improving pregnancy outcomes for women with diabetes', *Practical Diabetes International*, 25, pp. 172–174.
- Howe, K. (1988) 'Against the quantitative–qualitative incompatibility thesis, or, dogmas die hard', *Educational Researcher*, 17, pp. 10–16.
- Hudson, J., Wentworth, S., Hudson, M. and Pope JR, H. (1985) 'Prevalence of anorexia nervosa and bulimia among young diabetic women', *Journal of Clinical Psychiatry*, 6, pp. 88–89.
- Hunt, D. and Smith, J. (2004) 'The personal experience of carers of stroke survivors: An interpretative phenomenological analysis', *Disability and Rehabilitation*, 26, pp. 1000–1011.
- Huxley, R., Barzi, F. and Woodward, M. (2006) 'Excess risk of fatal coronary heart disease associated with diabetes in men and women: meta-analysis of 37 prospective cohort studies', *British Medical Journal*, 332, pp. 73–76.
- Illich, I. (1975) *Medical Nemesis: The expropriation of health*, London, Calder and Boyars.
- Jarvis, S.R.P. (2003) 'Snoring, not just a social nuisance', *International Journal of Clinical Practice*, 57, pp. 788–791.
- Jedrzejuk, D. and Milewicz, A. (2005) 'Consequences of menopause in women with diabetes – a clinical problem', *Gynecological Endocrinology*, 21, pp. 280–286.
- Jerkins, T. (2001) *On Wings and Prayers - Living with diabetes one sugar at a time*, Austin, Texas USA, Langmarc Publishing.
- Johnson, B. and Macleod Clarke, J. (2003) 'Collecting sensitive data: The impact on researchers', *Qualitative Health Research*, 13, pp. 421–434.

- Josselson, R. and Lieblich, A. (eds) (1999) *Making Meaning of Narratives*, Thousand Oaks, Sage.
- Kanner, A.D., Coyne, J.C., Schaefer, C. and Lazarus, R.S. (1981) 'Comparison of two modes of stress measurement: daily hassles and uplifts versus major life events', *Journal of Behavioural Medicine*, 4, pp. 1–39.
- Kaplan, H.D. (1979) 'Social psychology of disease', in Freeman, H.G., Levine, S. and Reeder, L.F. (eds) *Handbook of Medical Sociology*, 3rd ed., Englewood Cliffs, N.J., Prentice-Hall.
- Kasl, S. (1995) 'Theory of stress and health', in Cooper, C. (ed.) *Handbook of Stress, Medicine and Health*, Florida, CRC.
- Katz, R. (1984) 'Empowerment and synergy: expanding the community's healing resources', *Prevention in Human Services*, 3, pp. 201–226.
- Kelleher, D. (1988) 'Coming to terms with diabetes: coping strategies and non-compliance', in Anderson, R. and Bury, M. (eds) *Living with Chronic Illness – The experience of patients and their families*, London, Unwin Hyman.
- Kieffer, C. (1984) 'Citizen empowerment: a development perspective', *Prevention in Human Services*, 3, pp. 9–36.
- Kingray, M., Tiedje, L. and Friedman, L. (1990) 'Focus Groups: a research technique for nursing', *Nursing Research*, 39, pp. 124–125.
- Kirkendall, D (2003) "'Just" an ankle sprain? It should not be seen as a nuisance but a serious injury', *Soccer Journal*, 48, pp. 42–44.
- Kitzinger, J. (1995) 'Qualitative research: Introducing focus groups', *BMJ*, 311, pp. 299–320.
- Kjaer, K., Hagen, C., Sando, S. and Eshoj, O. (1992) 'Epidemiology of menarche and menstrual disturbances in an unselected group of women with insulin-dependent diabetes mellitus compared to controls', *The Journal of Clinical Endocrinology and Metabolism*, 75, pp. 524–529.

- Kleinman, A. (1988) *The Illness Narratives- suffering, healing and the human condition*, New York, Basic Books.
- Koch, T., Kralik, D. and Sonnack, D. (1999) 'Women living with Type 2 diabetes: the intrusion of illness', *Journal of Clinical Nursing*, 8, pp. 712–722.
- Koch, T., Kralik, D. and Taylor, J. (2000) 'Men living with diabetes: minimising the intrusiveness of disease', *Journal of Clinical Nursing*, 9, pp. 247–254.
- Kohler Reissman, C. (1993) *Narrative analysis*, Newbury Park, California, Sage.
- Konen, J.C., Summerson, J.H. and Dignan, M.B. (1993) 'Family function, stress, and locus of control. Relationships to glycemia in adults with diabetes mellitus', *Arch Fam Med*, 2, pp. 393–402.
- Kralik, D. (2002) 'The quest for ordinariness: transition experienced by midlife women living with chronic illness', *Journal of Advanced Nursing*, 39, pp. 146–154.
- Kralik, D., Koch, T. and Brady, B. (2000) 'Pen pals: correspondence as a method for data collection in qualitative research', *Journal of Advanced Nursing*, 31, pp. 909–917.
- Kvale, S. (1996) *Interviews – An introduction to qualitative research interviewing*, Thousand Oaks, Sage.
- Lather, P. (1991) *Getting Smart: Feminist research and pedagogy within the Postmodern*, New York, Routledge.
- Lawton, J. and Rankin, D. (2010) 'How do structured education programmes work? An ethnographic investigation of the Dose Adjustment For Normal Eating (DAFNE) programme for type 1 diabetes patients in the UK', *Social Science and Medicine*, 71, pp. 486–493.
- Leckenby, D. and Hesse-Biber, S. (2007) 'Feminist approaches to mixed methods research', in Hesse-Biber, S. and Leavy, P. (eds) *Feminist Research Practice*, Thousand Oaks, CA, Sage.
- Levi, L. (1995) 'Spice of life or kiss of death?', in Cooper, C. (ed.) *Handbook of Stress, Medicine and Health*, Florida, CLC.

- Levine, M. and Marcus, M. (1997) 'Women, diabetes and disordered eating', *Diabetes Spectrum*, 10, pp. 191–195, 229–230.
- Lin, E., Katon, W., Von Korff, M., Rutter, C., Simon, G., Oliver, M., Ciechanowski, P., Ludman, E., Bush, T. and Young, B. (2004) 'Relationship of depression and diabetes self-care, medication adherence and preventive care', *Diabetes Care*, 27, pp. 2154–2160.
- Lincoln, Y. and Guba, E. (1985) *Naturalistic Enquiry*, Beverley Hills, California, Sage.
- Linn, T. and Bretzel, R.G. (1997) 'Diabetes in pregnancy', *Eur J Obstet Gynaecol Reprod Biol*, 75, pp. 37–41.
- Lloyd, C. and Orchard, T. (1999) 'Physical and psychological well-being in adults with Type 1 diabetes', *Diabetes Research and Clinical Practice*, 44, pp. 9–19.
- Lloyd, C. and Skinner, T. (2009) 'Policy and practice for diabetes care', in Denny, E. and Earle, S. (eds.) *The Sociology of Long Term Conditions and Nursing Practice*. London, Palgrave.
- Lloyd, C., Barnett, A. and Dyer, P. (2002) 'Effects of psychological symptomatology on diabetes management', *Diabetic Medicine*, 19, pp. 1–27.
- Lloyd, C., Dyer, P. and Barnett, A. (2000) 'Prevalence of symptoms of depression and anxiety in a diabetes clinic population', *Diabetic Medicine*, 17, pp. 198–202.
- Lloyd, C., Dyer, P., Lancashires, R., Harris, T., Daniels, J. and Barnett, A. (1999) 'Association between stress and glycaemic control in adults with type 1 (Insulin-Dependent) diabetes', *Diabetes Care*, 22, pp. 1278–1282.
- Lloyd, C., Hill, J., Webb, J. and Tahrani, A. (2008) 'Challenges to good diabetes care', in Barnett, A. (ed.) *Management of Type 2 Diabetes*, New York, Oxford University Press.
- Lloyd, C., Smith, J. and Weinger, K. (2005) 'Stress and diabetes: a review of the links', *Diabetes Spectrum*, 18, pp. 121–127.

- Lloyd, C., Wing, R. and Orchard, T. (1996) 'Waist to hip ratio and psychosocial factors in adults with IDDM: the Pittsburgh Epidemiology of Diabetes Complications Study', *Metabolism*, 45, pp. 268–272.
- London, O. and Gabbe, R. (1992) 'Diabetes mellitus and pregnancy', *Obstetrics and Gynaecology Clinics of North America*, 19, pp. 633–654.
- Lorber, J. (1997) *Gender and the Social Construction of Illness*, Thousand Oaks, Sage.
- Lorde, A. (2007) 'Poetry is not a luxury', in Lorde, A. (ed.) *Sister Outsider*, Freedom: CA, The Crossing Press.
- Lovell, M.C. (1982) 'Daddy's little girl: the lethal effects of paternalism in nursing', in Muff, J. (ed.) *Socialisation, Sexism and Stereotyping: Women's issues in nursing*, St. Louis, C.V. Mosby.
- Lustman, P., Carney, R. and Amado, H. (1981) 'Acute stress and metabolism in diabetes', *Diabetes Care*, 4, pp. 658–659.
- Lutfey, K. and Wishner, W. (1999) 'Beyond "compliance" is "adherence" – Improving the prospect of diabetes care', *Diabetes Care*, 22, pp. 635–639.
- MacPherson, K.I. (1983) 'Feminist methods: a new paradigm for nursing research', *Advances in Nursing Science*, 5, pp. 17–25.
- Maillet, N., D'Eramomelkus, G. and Spollett, G. (1996) 'Using focus groups to characterise the health beliefs and practices of black women with non-insulin dependent diabetes', *The Diabetes Educator*, 22, pp. 39–45.
- Mason, D.J., Backer, B.A. and Georges, C.A. (1991) 'Towards a feminist model for the political empowerment of nurses', *Image: Journal of Nursing Scholarship*, 23, pp. 72–77.
- Maynard, M. (1994) 'Methods, practice and epistemology: The debate about feminism and research', in Maynard, M. and Purvis, J. (eds) *Researching Women's Lives from a Feminist Perspective*, London, Taylor and Francis.

- Maynard, M. and Purvis, J. (eds) (1994) *Researching Women's Lives from a Feminist Perspective*, London, Taylor and Francis.
- McCabe, J. and Holmes, D. (2009) 'Reflexivity, critical qualitative research and emancipation: A Foucauldian perspective', *Journal of Advanced Nursing*, 65, pp. 1518–1526.
- Mertens, D. (2003) 'Mixed methods and the politics of human research: The transformative—emancipatory perspective', in Tashakkori, A. and Teddlе, C. (eds) *Handbook of Mixed Methods in Social and Behavioral Research*, Thousand Oaks, CA, Sage.
- Metsch, J., Tillil, H., Köbberling, J. and Sartory, G. (1995) 'On the relation among psychological distress, diabetes-related health behavior, and level of glycosylated hemoglobin in Type I diabetes', *International Journal of Behavioural Medicine*, 2, pp. 104–117.
- Mezuk, B., Eaton, W., Albrecht, S. and Golden, S. (2008) 'Depression and Type 2 diabetes over the lifespan: a meta-analysis', *Diabetes Care*, 31, pp. 2383–2390.
- Mies, M. (1993) 'Towards a methodology for feminist research', in Hammersley, M. (ed.) *Social Research: Philosophy, politics and practice*, London, Sage.
- Mies, M. (1983) 'Towards a methodology for feminist research', in Bowles, G. and Duelli Klein, R. (eds) *Theories of Women's Studies*, London, Routledge and Kegan Paul.
- Miller, W. and Crabtree, B. (2000) 'Clinical research', in Denzin, N. and Lincoln, Y. (eds) *Handbook of Qualitative Research*, 2nd ed, Thousand Oaks, California, Sage.
- Morgan, D. L. (1988) *Focus Groups as Qualitative Research*, Thousand Oaks, Sage.
- Morris, J., Povey, R. and Street, C. (2005) Experiences of people who have changed from oral medication to self-administered insulin injections, *Practical Diabetes International*, 22, pp. 239–243.
- Nacher, M. (2002) 'Worms and malaria: noisy nuisances and silent benefits', *Parasite Immunology*, 24, pp. 391–393.

- Napholz, L. (2000) 'Balancing multiple roles among a group of urban midlife American Indian working women', *Health Care for Women International*, 21, p. 255.
- National Institute for Health and Clinical Excellence (NICE) (2008) *Diabetes in Pregnancy*, London, NICE.
- Nyatanga, L. and Dann, K. (2002) 'Empowerment in nursing: the role of philosophical and psychological factors', *Nursing Philosophy*, 3, pp. 234–239.
- Oakley, A. (1993) *Essays on women, medicine and health*, Edinburgh, Edinburgh University Press.
- Oakley, A. (1981) 'Interviewing women: a contradiction in terms', in Roberts, H. (ed.) *Doing Feminist Research*, London, Routledge and Kegan Paul.
- Oiler Boyd, C. (1993) 'Philosophical foundations of qualitative research', in Munhall, P. and Oiler Boyd, C. (eds) *Nursing research – a qualitative perspective*. 2nd ed., New York, National League for Nursing Press.
- Opie, A. (1998) "'Nobody's asked me for my view"; Users' empowerment by multidisciplinary health teams', *Qualitative Health Research*, 8, pp. 188–06.
- Opie, A. (1992) 'Qualitative research, appropriation of the "other" and empowerment', *Feminist Review*, 40, pp. 52–69.
- Osborn, M. and Smith, J. (1998) The personal experience of chronic benign low back pain: An interpretative phenomenological analysis, *British Journal of Health Psychology*, 3, pp. 65–83.
- Packard, N., Haberman, M., Fugate Woods, N. and Yates, B. (1991) 'Demands of illness among chronically ill women', *Western Journal of Nursing Research*, 13, pp. 434–457.
- Parsons, T. (1975) 'The sick role and the role of the physician reconsidered', *Milbank Memorial Fund Quarterly Health and Society*, 53, pp. 257–278.
- Patel, J. (1993) 'Empowerment of diabetics: a challenge for community nursing', *British Journal of Nursing*, 2, 407–409.

- Paterson, B. (2001) 'Myth of empowerment in chronic illness', *Journal of Advanced Nursing*, 34, pp. 574–581.
- Patton, M.Q. (1990) *Qualitative Evaluation and Research Methods*, Newbury Park, California, Sage.
- Personal Narratives Group (1989) *Interpreting Women's Lives: Feminist Theory and Personal Narratives*, Bloomsbury, Indiana University Press.
- Peveler, R., Fairburn, C., Boller, I. and Dunger, D. (1992) 'Eating disorders in adolescents with IDDM: a controlled study', *Diabetes Care*, 15, pp. 1356–1360.
- Peyrot, M., McMurray, J. Jr. and Hedges, R. (1987) 'Living with diabetes: the role of personal and professional knowledge in symptom and regimen management', in Brooks, N. and Matson, R. (eds) *Research in the Sociology of Health Care*, Vol. 6., Greenwich, Connecticut, JAI Press Inc, pp. 107–146.
- Peyrot, M., Rubin, R., Lauritzen, T., Snoek, F., Matthews, D. and Skovlund, S. (2005) 'Psychosocial problems and barriers to improved diabetes management: results of the cross-national diabetes attitudes, wishes and needs (DAWN) study', *Diabetic Medicine*, 22, pp. 1379–1385.
- Plach, S., Stevens, P. and Moss, V. (2004) 'Social role experiences of women living with rheumatoid arthritis', *Journal of Family Nursing*, 10, pp. 33–49.
- Plummer, K. (1983) *Documents of Life – An introduction to the problems and literature of a humanistic method*, London, George Allen and Unwin.
- Polonsky, W. (1999) *Diabetes Burnout: what to do when you can't take it any more*, Alexandria, Virginia, American Diabetes Association.
- Polonsky, W. and Anderson, B. (1995) 'Insulin omission in women with IDDM', *Journal of the American Dietetic Association*, 95, pp. 500–506.
- Polonsky, W., Anderson, B., Lohrer, P., Aponte, J., Jacobson, A. and Cole, C. (1994) 'Insulin omission in women with IDDM', *Diabetes Care*, 17, pp. 1178–1185.

- Powell, R. and Single, H. (1996) 'Focus groups', *International Journal of Quality in Health Care*, 8, pp. 499–504.
- Price, H., Dudley, C., Barrow, B., Kennedy, I., Griffin, S. and Holman, R. (2009) 'Use of focus groups to develop methods to communicate cardiovascular disease risk and potential for risk reduction to people with type 2 diabetes', *Family Practice*, 26, p. 351.
- Probert, C., Maddison, W. and Roland, J. (1990) 'Diet, diabetes and male chauvinism', *British Medical Journal*, 301, pp. 1430–1431.
- Rager, K. (2005) 'Compassion stress and the qualitative researcher', *Qualitative Health Research*, vol. 15, no. 3, pp. 423–430.
- Rapaport, W.S., LaGreca, A.M. and Levaine, P. (1996) 'Preventing eating disorders in young women with type 1 diabetes', in Rubin, R. and Anderson, B. (eds) *Practical Psychology for Diabetes Clinicians*, Alexandria, VA, American Diabetes Association.
- Rappaport, J. (1984) 'Studies in empowerment: Introduction to the issue', *Prevention in Human Services*, 3, pp. 1–7.
- Rapport, F. and Sparkes, A.C. (2009) 'Narrating the Holocaust: In pursuit of poetic representations of health', *Medical Humanities*, 35, pp. 27–34.
- Reid, J. and Hardy, M. (1999) 'Multiple roles and well-being among midlife women: testing role strain and role enhancement theories', *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 54B, S329.
- Reinharz, S. (1992) *Feminist methods in social research*, New York, Oxford University Press.
- Reynolds, F. and Prior, S. (2003) 'A Lifestyle Coat Hanger': a phenomenological study of the meanings of artwork for women coping with chronic illness and disability, *Disability and Rehabilitation*, 25, pp. 785–794.
- Reynolds, P. (1972) 'The protection of human subjects and social science', *International Social Science journal*, 24, pp. 693–719.

- Rezen, S.V. (2005) 'A reason for concern: a hearing loss in one ear is much more than a nuisance and is definitely something to worry about', *Hearing|Loss Magazine*, 26, p. 22.
- Ribbens, J. (1989) 'Interviewing – An unnatural situation?', *Women's Studies International Forum*, 12, pp. 579–592.
- Richards, G., Morris, M., Booker, S. and Johnson, A. (2006) 'What do people with Type 1 diabetes find helpful in health professionals? Results from a focus group study', *Practical Diabetes International*, 23, pp. 249–252.
- Richardson, L. (2000) Writing; a method of inquiry, in Denzin, N. and Lincoln, Y. (eds) *Handbook of Qualitative Research*, Second ed., London, Sage.
- Richardson, L. and Adams St. Pierre, E. (2005) 'Writing: a method of enquiry', in Denzin, N. and Lincoln, Y. (eds) *The Sage Handbook of Qualitative Research*, 3rd ed., Thousand Oaks, California, Sage.
- Roberts, H. (ed.) (1992) *Women's health matters*, London, Routledge.
- Robinson, N., Fuller, H. and Edmeades, S. (1988) 'Depression and diabetes', *Diabetic Medicine*, 5, pp. 268–274.
- Robinson, N. and Fuller, J. (1985) 'Role of life events and difficulties in the onset of diabetes mellitus', *Journal of Psychosomatic Research*, 29, pp. 583–591.
- Robson, C. (1993) *Real World Research: a resource for social scientists and practitioner-researchers*, Oxford, Blackwell.
- Rockcliffe-Fidler, C. and Kiemle, G. (2003) 'Sexual function in diabetic women: a psychological perspective', *Sexual and Relationship Therapy*, 18, pp. 143–59.
- Rodin, G., Daneman, D., Johnson, L., Kenshole, A. and Garfinke, P. (1985) 'Anorexia nervosa and bulimia in female adolescents with insulin dependent diabetes mellitus: a systematic study', *Journal of Psychiatric Research*, 19, pp. 381–384.
- Roger, K.S. (2007) 'It's a problem for other people, because I am seen as a nuisance: hearing the voices of people with dementia', *Alzheimer's Care Quarterly*, 8, pp. 17–25.

- Roney, L. (1999) *Sweet Invisible Body*, New York, Henry Holt.
- Roush, K. (2005) 'Not just a nuisance: one women with secondary Raynaud phenomenon copes with severe symptoms', *American Journal of Nursing*, 105, p. 58.
- Royer, A. (1998) *Life with Chronic Illness: Social and psychological dimensions*, Westport, CT, London, Praeger.
- Rubin, R. (1998) 'Behavior change', in Funnell, M., Hunt, C., Kulkarni, K., Rubin, R. and Yarborough, P. (eds) *A Core Curriculum for Diabetes Education*, Chicago, American Association of Diabetes Educators.
- Rubin, R. and Peyrot, M. (1998) 'Men and diabetes: psychosocial and behavioural issues', *Diabetes Spectrum*, 11, pp. 81–87.
- Rubin, R.R. and Peyrot, M. (1992) 'Psychosocial problems and interventions in diabetes', *Diabetes Care*, 15, pp. 1640–1657.
- Sandelowski, M. (1993) 'Rigor or rigor mortis: the problem of rigor in qualitative research revisited', *Advances in Nursing Science*, 16, 1–8.
- Saxton, M. and Howe, F. (eds) (1988) *With Wings*, London, Virago.
- Scanlon, J. (1993) 'Challenging the imbalances of power in feminist oral history: Developing a take-and-give methodology', *Women's Studies International Forum*, 16, pp. 639–645.
- Scott, M.J. and Stradling, S.G. (1994) 'Post-traumatic stress disorder without the trauma', *British Journal of Clinical Psychology*, 33, pp. 71–74.
- Selye, H. (1956) *The Stress of Life*, New York, McGraw-Hill Book Company.
- Shah, H. (1989) 'Psychosocial adjustment, self-concept and sexual satisfaction of women with diabetes', *Dissertation Abstracts International*, 50, 4456B.
- Shalev, A., Schreiber, S., Galai, T. and Melmed, R. (1993) 'Post-traumatic stress disorder following medical events', *British Journal of Clinical Psychology*, 32, pp. 247–253.

- Shapiro, M., D, S. and Cragg, C. (2003) 'Capturing the complexity of women's experiences: a mixed methods approach to studying incontinence in older women', *Affilia: Journal of Women and Social Work*, 18, pp. 21–33.
- Sherwin, S. (1992) *No longer patient: feminist ethics and health care*, Philadelphia, Temple University Press.
- Shu-Ki Tse, S. (1999) 'The nuisance factor: A study of daily stress for people with long-term psychiatric disabilities', *Journal of Rehabilitation*, 65, p. 6.
- Silverman, D. (1987) *Communication and Medical Practice – social relations in the clinic*, London, Sage.
- Silverman, D. (1983) 'Interview talk: bringing off a research instrument', *Sociology*, 17, pp. 31–47.
- Skelton, R. (1994) 'Nursing and empowerment: concepts and strategies', *Journal of Advanced Nursing*, 19, pp. 415–423.
- Skinner, C. and Cradock, S. (2001) 'Empowerment-a response', *Practical Diabetes*, 18, 26.
- Skinner, C.T. and Cradock, S. (2000) 'Empowerment: what about the evidence', *Practical Diabetes International*, 17, pp. 91–95.
- Smith, D. (1987) *The Everyday World as Problematic*, Milton Keynes, The Open University Press.
- Smith, J. (1994) 'Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology', *Psychology and Health*, 11, pp. 261–271.
- Smith, J., Jarman, M. and Osborn, M. (1999) 'Doing interpretative phenomenological analysis', in Murray, M. and Chamberlain, K. (eds) *Qualitative Health Psychology*, London, Sage.
- Smith, J. and Eatough, V. (2007) 'Interpretative phenomenological analysis', in Lyons, E. and Coyle, A. (eds) *Analysing Qualitative Data in Psychology*, London, Sage.

- Smith, J.A. (ed.) (2009) *Qualitative Psychology. A practical guide to methods*, London, Sage.
- Smith, J.A., Flowers, P. and Larkin, M. (2009) *Interpretative Phenomenological Analysis. Theory, Method and Research*, London, Sage.
- Sparkes, A.C. (2009) 'Novel ethnographic representations and the dilemmas of judgement', *Ethnography and Education*, 4, pp. 301–319.
- Sparkes, A.C. (2002) *Telling Tales in Sport and Physical Activity: A qualitative journey*, Leeds, UK, Human Kinetics.
- Sparkes, A.C. (1998) 'Validity in qualitative inquiry and the problem of criteria: implications for sport psychology', *The Sport Psychologist*, 12, pp. 363–386.
- Sparkes, A.C. and Douglas, K. (2007) 'Making the case for poetic representation: an example in action', *The Sport Psychologist*, 21, pp. 170–190.
- Sparkes, A.C. and Smith, B. (2009) 'Judging the quality of qualitative inquiry: Criteriology and relativism in action', *Psychology of Sport and Exercise*, 10, pp. 491–497.
- St John, W., James, H. and Mckenzie, S. (2002) "'Oh, that's a bit of a nuisance": community-dwelling clients' perspectives of urinary continence health service provision', *Journal of Wound, Ostomy and Continence Nursing*, vol. 29, no. 6, pp. 312–319.
- Stabler, B., Surwit, R. and Lane, J.E.A. (1987) 'Type A behavior pattern and blood glucose control in diabetic children', *Psychosomatic Medicine*, 49, pp. 313–316.
- Stanley, L. and Wise, S. (1983) *Breaking out; feminist consciousness and feminist research*, London, Routledge and Kegan Paul.
- Stanley, L. and Wise, S. (1993) *Breaking Out Again - Feminist Ontology and Epistemology*, London, Routledge.
- Stenstrom, U., Wikby, A., Hornquist, J. and Andersson, P. (1993) 'Recent life events, gender and the control of diabetes mellitus', *General Hospital Psychiatry*, 15, pp. 82–88.

- Strauss, A., Corbin, J., Fagerhaugh, S., Glaser, B., Mannes, D., Suczeck, B. and Wiener, C. (1985) *Chronic Illness and the Quality of Life*, St Louis, Mosby.
- Strote, M.E. (2004) "'Minor" STD, not just a nuisance', *Shape*, 24, p. 124.
- Surwit, R.S. and Schneider, M.S. (1993) 'Role of stress in the etiology and treatment of diabetes mellitus', *Psychosom Med*, 55, pp. 380–93.
- Surwit, R.S., Schneider, M.S. and Feinglos, M.N. (1992) 'Stress and diabetes mellitus', *Diabetes Care*, 15, pp. 1413–22.
- Swanson, J. (1986) 'The formal qualitative interview for grounded theory', in Chenitz, W. and Swanson, J. (eds) *From Practice to Grounded Theory: Qualitative Research in Nursing*, Wokingham, Berkshire, Addison-Wesley.
- Symonds, J. and Gorard, S. (2010) 'Death of mixed methods? Or the rebirth of research as a craft?', *Evaluation and Research In Education*, 23, pp. 121–136.
- Szasz, T. and Hollender, M. (1956) 'A contribution to the philosophy of medicine: the basic models of the doctor-patient relationship', *American Medical Association Archives of Internal Medicine*, 97, pp. 585–592.
- Tashakkori, A. and Teddle, C. (eds) (2003) *Mixed Methods in Social and Behavioral Research*, Thousand Oaks, Sage.
- Taylor, S.J. and Bogdan, R. (1984) *Introduction to Qualitative Research Methods – The search for meanings*, New York, John Wiley and Sons.
- Thomas, S.L.E.C. (2000) 'Nuisance or natural and health: should monthly menstruation be optional for women?', *Lancet*, 11 March, pp. 922–924.
- Trostle, J. (1988) 'Medical compliance as an ideology', *Social Science and Medicine*, 27, pp. 1299–1308.
- Tuckett, D., Boulton, M., Olson, C. and Williams, A. (1985) *Meetings Between Experts – an approach to sharing ideas in medical consultations*, London.

- Vandenbergh, R.L., Sussman, K.E. and Vaughan, G.D. (1967) 'Effects of combined physical-anticipatory stress on carbohydrate-lipid metabolism in patients with diabetes mellitus', *Psychosomatics*, 8, pp. 16–19.
- Waddock, S. and Spangler, E. (2000) 'Action learning in leadership for change: Partnership, pedagogy, and projects for responsible management development', in Sherman, F. and Torbert, W. (eds) *Transforming social inquiry, transforming social action; New paradigms for crossing the theory/practice divide in universities and communities*, Boston, Kluwer.
- Walker, R. (1998) 'Diabetes: Reflecting on empowerment', (RCN Continuing Education, article 432. 16 refs). *Nursing Standard*, 12, pp. 49–56.
- Waterston, J. (1995) *Funny, You Don't Look Like a Diabetic*, Bath, Ashgrove Press.
- Watkins, P., Drury, P. and Howell, S. (1996) *Diabetes and its Management*, Oxford, Blackwell.
- Weedon, C. (1987) *Feminist Practice and Poststructuralist Theory*, Oxford, Blackwell.
- Wheeler, C. and Chin, P. (1989) *Peace and Power: A handbook of feminist process*, New York, National League for Nursing.
- White, N., Richter, J. and Fry, C. (1992) 'Coping, social support and adaptation to chronic illness', *Western Journal of Nursing Research*, 14, pp. 211–224.
- Wild, D., Von Maltzahn, R., Brohan, E., Christensen, T., Clauson, P. and Gonder-Frederick, L. (2007) 'A critical review of the literature on fear of hypoglycaemia in diabetes: implications for diabetes management and patient education', *Patient Education and Counselling*, 68, pp. 10–15.
- Wilkinson, S. (1999) 'How useful are focus groups in feminist research?', in Barbour, R. and Kitzinger, J. (eds) *Developing Focus Group Research*, 1st ed, London, Sage.
- Wilkinson, S. (1998a) 'Focus groups in feminist research: Power, interaction and the co construction of meaning', *Women's Studies International Forum*, 21, pp. 111–125.

- Wilkinson, S. (1998b) 'Focus Groups in health research', *Journal of Health Psychology*, 3, pp. 329–348.
- Williams, G. and Pickup, J. (2004) *Handbook of Diabetes*, Oxford, Blackwell.
- Willis, T. (1684) *Practice of Physick: Treatise II. Pharmaceutice Rationalise*, London, Dring, Hayer and Leigh.
- Woods, N., Haberman, M. and Packard, N. (1993) 'Demands of illness and individual, dyadic and family adaptation in chronic illness', *Western Journal of Nursing Research*, 15, pp. 10–25.
- Woods, N. and Lewis, F. (1995) 'Women and chronic illness, their views of their families' adaptation', *Health Care Women International*, 16, pp. 135–148.
- Wuest, J. (2000) 'Repatterning care: women's proactive management of family caregiving demands', *Health Care for Women International*, 21, pp. 393–411.
- Yardley, L. (2008) 'Demonstrating validity in qualitative psychology', in Smith, J. (ed.) *Qualitative Psychology: A practical guide to research methods*, London, Sage.
- Zimmerman, D. and Wieder, D. (1977) 'The diary – Interview method', *Urban Life*, 5, pp. 479–498.

Appendix 1

Consent form for Focus Group

CONSENT FORM

Name of participant:

Project title: Women living with diabetes

Name of researcher: Julie Smith –supervised by Cathy Lloyd and Ann Brechin

1.I confirm that I have read and understood the information sheet dated..... for the above study and have had the opportunity to ask questions

2.I understand that my participation is voluntary and that I am free to withdraw at any time and have the right to refuse the use of any information that I have already given.

3.I have been informed that the confidentiality of the information I provide will be safeguarded and I give permission for the use of anonymised quotations in written reports and published materials.

4.I agree to take part in the above study.

Name of participant.....

Signature.....

Name of researcher.....

Signature.....

Date.....

Appendix 2

Living with diabetes questionnaire

THE EXPERIENCE OF WOMEN LIVING WITH DIABETES

Thank you for agreeing to take part in this research. It would be helpful if you could complete this questionnaire and return it to me in the envelope provided. All information is, of course, confidential and you are not obliged to answer questions with which you feel uncomfortable.

I would like to start by asking you a few questions about yourself

1. How old are you?
- 18 – 20

21 – 30

31 – 40

41 – 50

51 – 60

61 – 70

71 – 80

Over 80
- ☐

☐

☐

☐

☐

☐

☐

☐

2. Please indicate your ethnic origin by ticking the appropriate box

Asian Codes

- E Asian-British

C Bangladeshi

D Chinese
- A Indian

B Pakistani

F Asian-other
- ☐

☐

☐

☐

☐

☐

White codes

- L White-British

N White

-other European
- P White-other
- ☐

☐

☐

☐

Black codes

- J Black-British

H Black-African
- G Black-Caribbean

K Black-other
- ☐

☐

☐

☐

Others

- R Any other ethnic group
- ☐

[illegible]

If yes, what is your job?.....

If no, please go to Question 5.

[illegible]

5. Would you describe yourself as? (Please tick one box)

Living alone ☐

Living with a partner/spouse ☐

Living with your family ☐

Other

Please list the people that make up your household e.g. partner, parents, children, friend...

[illegible]

If yes, please state how many and their age(s).....
.....

7. Please identify anyone else for whom you have a caring role e.g. elderly parents, disabled household members.....

Your diabetes

8. How long have you had diabetes?.....years

9. How long have you been taking insulin?.....years

10. Do any other members of your family have diabetes? Yes ☐
No ☐

If yes, who?.....
.....

11. Who do you feel gives you the most support in relation to your diabetes?.....
.....

12. If you had a problem with your diabetes, whose advice would you seek?
Please tick as many boxes as are relevant to you.

Friend ☐

Relative ☐

Community Nurse ☐

Practice Nurse ☐

Hospital Nurse ☐

General Practitioner ☐

Hospital Doctor ☐

Diabetic Consultant ☐

Dietitian ☐

Other –please state.....

13. Of the people that you have identified, who do you find it easiest to talk to?.....
.....

14. How would you describe your feelings *before* you are due to see a health care professional about your diabetes?.....
.....
.....
.....

15. How would you describe your feelings *after* you have seen a health care professional about your diabetes?.....
.....
.....
.....

16. Who do you feel is in charge of your diabetes?.....
.....

17. Does diabetes affect your daily life and work? Yes ☐
No ☐

If yes, in what way?.....
.....

18. Do you find living with diabetes stressful? Yes ☐

 No ☐

If yes, what things are particularly difficult for you?.....
.....
.....
.....

[illegible]

If so, please explain how

.....

.....

.....

[illegible]

If so, please explain how

.....

.....

.....

General Stress

21. In general, how do you feel when you are stressed?.....
.....
.....
.....

22. How do you react when you are stressed?.....
.....
.....
.....

Please feel free to add anything about your experience of living with diabetes, which you would like to share, about which I have not asked.....
.....
.....

Many thanks for taking the time to complete this questionnaire

Julie Smith

Researcher

Appendix 3

Interview schedule

Introduction

Thank you for agreeing to talk to me today. Just to remind you that the purpose of the study is to look at women's experiences of having diabetes-what it is really like to live day to day with it. I hope to acknowledge women with diabetes as the experts. to give a more complete picture of the impact of diabetes on women's lives.

I would like to stress again that anything you say to me will not be traced back to you by anyone else. It is confidential and no health care professionals involved in your care will be contacted.

I would like to tape record our conversation if you are willing, so that I can concentrate on what you are saying to me, rather than writing too many notes at the same time that you are speaking. I may make a few notes as we go along to remind me to ask about anything that you raise. Let me know if you wish me to stop recording at any time.

Some people have had diabetes for longer than they have been taking insulin. Can I just check that you have had diabetes for x years and have been taking insulin for x years? For this conversation, I would like to focus on the time since you began taking insulin.

1.Living with diabetes

LOOK AT QUESTIONNAIRE

It would be helpful if I could remind myself of some of the details that you filled in on your questionnaire. You are x years old; either do or don't work outside the home as; live with x, y,z; have x children aged....), you care for x,

Please could you tell me about your experience of living with diabetes?

You are x years old and you have had insulin treated diabetes for x years. How would you describe the impact that diabetes has had on your life until now since you started insulin?

Do you feel particular areas of your life have been affected by diabetes?. In what way?

Do you feel that there are areas of your life which have affected your diabetes? In what way?

It would be helpful if you could think of a day recently that was typical for you. Could you describe that day to me-what happened during the day.

What words come to mind when you think about living with diabetes?

How would you describe the experience of living with diabetes to another woman who is newly diagnosed?

2.Work

*I would like to look at the issue of work **(either in or out of the home)***

Has work affected your diabetes? Please can you describe to me in what way

Has having diabetes affected your work? How?

3.Relationships

Who are the most important people in your life?

Does your relationship with them affect your diabetes?

Are they affected by your diabetes?

You mentioned that x also has diabetes in your family. Do you feel that this has affected your diabetes?

Does the fact that you have diabetes affect this relationship?

Do other people affect your diabetes?

Does your diabetes affect other people?

4.Roles

How does your role as a wife, mother etc affect your diabetes?

How does diabetes affect your role as....?

Are there other things that you do?

Does your diabetes affect.....

Is your diabetes affected by doing.....

5.Control

You said in your questionnaire that you are in charge of your diabetes? Why do think that this is?

What does the word 'control' mean to you?

What things make you feel that you are in control?

What things make you feel that you are not in control?

What do you do to be in control?

6.Support

In your questionnaire, you identified x as giving you the most support in relation to your diabetes? Why do think that this is?

Who else has given, or do you think could give you, support ?

*You said that if you had a problem with your diabetes you would seek x's advice .
Why do you find it easiest to talk to x?*

Where else do you find information about your diabetes?

I would like to remind you that anything you say to me is in confidence and I will not divulge the identity of anyone who has taken part in this study to any health care professionals or anyone else outside of this room.

7. Health Care Professionals

Please could you describe the relationships that you have had with health professionals involved in your care

What do you feel is the role of health professionals in the care of your diabetes? How far has this been your experience?

How would you describe your diabetes to a new health professional involved in your care? What would you like to say to them?

8. Stress in general

I would now like to talk to you about stress in general

What does the word 'stress' mean to you?

Tell me how you experience stress, personally

Could you please describe any single event in your life that you have found particularly stressful since you started taking insulin?

How did this affect your diabetes?

Was the event affected by your diabetes?

Could you please describe any situations in your daily life that you find particularly stressful?

Are they affected by your diabetes?

How do these affect your diabetes?

What sort of things do you find helpful when you are stressed?

What do you find unhelpful when you are stressed?

How do you cope with stress

9. Stress and diabetes

I would like to talk about your experience of stress and diabetes

Tell me about your experience of stress in relation to your diabetes – what, if anything, do you find stressful about living with diabetes?

What is the most stressful thing in your life relating to your diabetes?

What effect does stress have on your diabetes?

Does having diabetes affect your experience of stress?

Does stress affect the way that you manage your diabetes?

Does having diabetes affect the way that you cope with stress?

How do you see the relationship between stress and diabetes? (Do you think one affects the other? If so, how?)

10. Conclusion

When we spoke on the phone/exchanged e-mails/looked at your questionnaire you identified the certain issues as being important. Could we talk about these in more detail now, please?

Is there anything about your experience of living with diabetes that you would like to share with me, which I have not asked you about?

If there is anything that you would like to discuss with me later, please feel free to contact me – the details are on this card. I have also written the number of the Diabetes UK Careline, a confidential information service, on the back, together with the hours during which you can contact them, in case there are any other diabetes related issues that you wish to discuss - give card

I would like to leave this notebook with you, in which you can record your experiences of living with diabetes during the next 12 weeks. -go through instructions with them

Arrange to contact them after 6 weeks to check their progress

Are there any questions that you would like to ask me?

Thank you again for your important contribution to this research.

Appendix 4

Confidentiality agreement

Name of participant

Project title: Women living with diabetes

Name of researcher : Julie Smith supervised by Cathy Lloyd and Jeanne Katz

This agreement refers to the undertaking of a face to face interview and recording of qualitative data in a personal journal, for the purpose of the above research project, which has been scrutinised from an ethical point of view within the Open University.

As a researcher, I undertake to keep all information given to me both anonymous and confidential. I will not discuss the specific content with any other person, other than my supervisors.

If you give permission to tape record the interview, I will return the tape to you, if you so wish.

Signature of researcher..... Date.....

Signature of participant..... Date.....

CONSENT FORM

Name of participant:

Project title: Women living with diabetes

Name of researcher: Julie Smith –supervised by Cathy Lloyd and Ann Brechin

1.I confirm that I have read and understood the information sheet dated..... for the above study and have had the opportunity to ask questions

2.I understand that my participation is voluntary and that I am free to withdraw at any time and have the right to refuse the use of any information that I have already given.

3.I have been informed that the confidentiality of the information I provide will be safeguarded and I give permission for the use of anonymised quotations in written reports and published materials.

4.I agree to take part in the above study.

Name of participant.....

Signature.....

Name of researcher.....

Signature.....

Date.....